DOCUMENT RESUME

ED 304 801 EC 212 291

AUTHOR	Kelker, Katharin A.
TITLE	Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps. Second Edition.
INSTITUTION	Portland State Univ., OR. Research and Training Center to Improve Services to Emotionally Handicapped Children and Their Families.
SPONS AGENCY	National Inst. of Mental Health (DHHS), Rockville, Md.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	Aug 88
GRANT	G0084351137
NOTE	116p.; For first edition, see ED 293 287; for a related document, see ED 288 328.
AVAILABLE FROM	Resource Services Coordinator, Portland State University, Research and Training Center, Regional Research Institute for Human Services, P.O. Box 751, Portland, OR 97207-0751 ($7.00).
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC05 Plus Postage.
DESCRIPTORS	Behavior Problems; *Child Rearing; Coping; Counseling Services; Court Litigation; Delivery Systems; *Educational Diagnosis; Elementary Secondary Education; *Emotional Disturbances; *Federal Legislation; *Handicap Identification; *Intervention; Models; Preschool Education; Specialists

ABSTRACT

This handbook was written to share the feelings, experiences, and knowledge of parents of children with emotional disturbances. The first chapter, "Feelings Come First," examines the difficulty in identifying the causes of emotional disturbances, their impact on the family, and coping strategies. The second chapter, "Finding Some Help," describes models to explain emotional disturbance and common conditions exhibited by children and youth with emotional disturbance, such as disruptive behavior disorders, anxiety disorders, developmental disorders, mood disorders, etc. It also discusses specialists who provide diagnosis and treatment and services such as outpatient treatment, day treatment, residential treatment, and respite services. The final chapter, "Understanding the Law," reviews the meaning of some common labels applied to children with emotional disturbances; explores federal legislation and case law relevant to special education services; and addresses school and treatment problems, such as suspensions, expulsions, drug or alcohol problems, and so on. At the end of each chapter are exercises to review information or share attitudes and ideas. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED304801

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it
☐ Minor changes have been made to improve reproduction quality
- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

Taking Charge:

A Handbook for Parents Whose Children Have Emotional Handicaps

---

EC 212291

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
M. C.
McMasters
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

TAKING CHARGE:
A HANDBOOK FOR PARENTS WHOSE CHILDREN HAVE EMOTIONAL HANDICAPS

Katharin A. Kelker
Parents - Let's Unite for Kids (PLUK)
Billings, Montana

Loretta Norman, Editor
Barbara Friesen, Principal Investigator

Produced and Distributed by:

Families as Allies Project
Research and Training Center to Improve
Services for Seriously Emotionally
Handicapped Children and Their Families
Regional Research Institute for Human Services
Portland State University
Portland, Oregon 97207-0751
(503) 464-4040

August 1988
Second Edition

This publication was developed with funding from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education and the National Institute of Mental Health, U.S. Department of Health and Human Services (NIDRR grant number G008435137). The content of this publication does not necessarily reflect the views or policies of the funding agencies.

ACKNOWLEDGEMENTS

The editor would like to acknowledge the work of many who helped with this document. Katharin A. Kelker is the author of the parents' handbook. Staff members of the Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families provided assistance in the editing phase. James Mason provided additional material for the handbook directed toward the special concerns of minority families with children who have emotional disturbances. Marilyn McManus reviewed the legal citations in the handbook to assure their accuracy and completeness. Terry Butler wrote the section in Chapter Two on respite services. The glossary was compiled by staff members of the Families as Allies Project. Katie Yoakum and Kaye Exo proofread the material several times in its editing. Barbara Friesen provided editorial advice and encouragement. Darcy Shell handled the layout and formatting of the document. A number of other members of the Research and Training Center also reviewed the handbook, and their suggestions and comments were subsequently incorporated. Two members of the Research and Training Center's National Advisory Committee, Richard Angell, M. D., and William Arroyo, M. D., suggested additions and improvements to the first edition of the handbook which are incorporated in the second printing. The cover photograph was taken by Marilyn McManus. The Families as Allies staff is responsible for the selection of the handbook's title. Their choice reflects a belief that *Taking Charge* best describes the spirit of Katharin Kelker's book for parents whose children have emotional handicaps.

TABLE OF CONTENTS

FOREWARD 1

CHAPTER ONE: FEELINGS COME FIRST 3

- **Feelings Come First** 3
  - Unusual Behavior 3
  - Causes Difficult to Find 4
- **Impact on the Family** 5
  - Parents' Reactions 5
    - Loss of Self-Esteem 5
    - Shame and Guilt 5
    - Sorrow 5
    - Denial 6
    - Withdrawal 6
    - Anger 6
    - Depression 6
    - Fear 6
    - Ambivalence 6
    - Confusion 7
  - Other Family Members' Reactions 7
- **Coping with a Handicapped Child** 8
  - Coming to Terms with Feelings 8
  - Advice from Other Parents 8
    - Accepting the Child 9
    - Taking Action 10
    - Accepting the Handicap 12
    - Becoming an Advocate 12
- **Exercises** 15
  - Questions 15
  - Answers 20
- **References/Bibliography** 21

CHAPTER TWO: FINDING SOME HELP 23

- **What is Psychotherapy?** 24
  - Models to Explain Emotional Disturbance 24
    - Behavioral Model 24
    - Biological Model 24
    - Bio-Psycho-Social Model 24
    - Ecological Model 24
    - Interactive Model 24

- Psychoanalytic Model 25

Common Conditions Exhibited by Children and Youth with Emotional Disturbance 26
- Disruptive Behavior Disorders 26
  - Attention-deficit Hyperactivity Disorder 26
  - Conduct Disorder 26
  - Oppositional Disorder 26
- Anxiety Disorders of Childhood or Adolescence 27
  - Separation Anxiety 27
  - Avoidant Disorder 27
  - Overanxious Disorder 27
  - Simple Phobia 27
  - Post-Traumatic Stress Disorder 27
- Developmental Disorders 28
  - Autistic Disorder 28
- Mood Disorders 28
  - Bipolar Disorder 28
  - Major Depressive Disorder 29
- Other Disorders of Infancy, Childhood or Adolescence 29
  - Identity Disorder 29
  - Adjustment Disorder 29
  - Schizophrenia 30
- Are Autistic Children Considered Severely Emotionally Disturbed? 30

Specialists Who Provide Diagnosis and Treatment 32
- Where should I take my child for a diagnosis? 32
- What does a neurologist do? 32
- What if the problem is definitely not physical? 32
- How should I choose a therapist for my child? 33
- What kinds of therapists are available? 34
  - Psychiatrist 34
  - Psychoanalyst 34
  - Psychologist 34
    - Clinical Psychologist 34
    - School Psychologist 34
  - Psychotherapist 34
  - Social Worker 34
    - Clinical Social Worker 35
    - Psychiatric Social Worker 35
  - Nurse 35
    - Psychiatric Nurse 35
  - Counselor 35
    - Family Counselor 35
    - Guidance Counselor 35
    - Christian Counselor 35
    - Indigenous Counselor 35
- Should I consider cost when choosing a therapist? 36

-7

Services Available for Children and Parents 37
- What types of services are available? 37
  - Home Intervention 37
  - School-Based Services 37
  - Community-Based Outpatient Treatment 38
  - Community-Based Day Treatment 38
  - Community-Based Residential Treatment 38
    - Foster Home Placement 38
    - Group Home Placement 39
  - Residential Treatment Centers 39
    - Residential Care 39
    - Psychiatric Hospital 39
  - Training School 39
- Are support services available for parents? 40
- Respite services 41

Exercises 43
- Questions 43
- Answers 52

References/Bibliography 55

CHAPTER THREE: UNDERSTANDING THE LAW 59

Labels 61
- What are some common labels and what do they mean? 61
  - Autism 61
  - Behavior Disordered 62
  - Brain-injured 62
  - Delinquent 62
  - Deviant 62
  - Seriously Emotionally Disturbed 62
  - Mentally Ill 62
  - Neurologically Impaired 62
  - Sociopath 62
  - Socially Maladjusted 62

Federal Statutory and Case Law 63
- What is FERPA? 63
- What is Section 504? 63
- What is PL 94-142? 63
- To what ages does P.L. 94-142 apply? 63
- What is an appropriate education? 64
- Do emotionally disturbed children qualify? 64
- Why are "socially maladjusted" children excluded? 65
- What is the difference between SED and BD? 66
- Does a "mentally ill" student qualify? 66
- Is psychotherapy a related service? 67
- Students' rights in the special education process 67
- Parents' rights in the special education process 68
- Can parent/family counseling be required? 69
- How important is the IEP? 70

What should an IEP contain? 70
What does "Least Restrictive Environment" mean? 70
How does LRE differ from mainstreaming? 70
What if parents consider their child's program inadequate? 71
What is a due process hearing? 71
Who pays for a hearing? for court? 71

School and Treatment Problems **72**
May an SED student be excluded from school? 72
May a special education student be suspended or expelled? 72
Short-term suspension 72
Long-term expulsion 73
Corporal punishment 74
Drug or alcohol problems 74
Chemical dependency 75
Residential treatment cost 75
Need to relinquish custody 76
What does adjudicated mean? 76
Losing custody 77
Correctional facility 77
State psychiatric institution 78
Emergency admission 78
Involuntary admission 78
Voluntary admission 78

Sources of Information about Mental Health Issues **79**

Exercises **81**
Questions 81
Answers 88

References/Bibliography **93**

GLOSSARY 95

Acronyms **95**

Laws and Regulations **100**

Terms **101**

FOREWARD

For all parents, preparing for the birth or adoption of a child involves a great deal of planning, dreaming, and even fantasizing. The unfulfilled aspirations of the expectant parents become woven into their dreams for the new child.

All parents fantasize in this way, but few children ever grow up to fulfill all the dreams of their parents. Gradually, parents adjust to their children as they are with their own strengths, weaknesses, and human frailities. Even though the child does not have the beauty, talent or winning personality that parents dreamed about, the child has real skills and strengths which are a source of pride.

Most parents accept their children as they are and expect them to grow up reasonably normally. Some children, however, are different. They do not fit normal patterns of development. They may appear normal physically and may also have normal intelligence, but their behavior does not conform to accepted standards. These "different" children are the ones who may be labeled "seriously emotionally disturbed" or "seriously emotionally handicapped."

We have written this handbook to share the feelings, experiences, and knowledge of other parents of children with emotional disturbances with you. Our purpose is to let you know that you are not alone. There are other parents struggling with problems similar to yours who understand your feelings and frustrations.

The chapters included in this handbook are "Feelings Come First," "Finding Some Help," and "Understanding the Law." At the end of each chapter, there are exercises to help you review information or share attitudes and ideas with others. You may want to read the chapters by yourself or with your spouse. You can use all or parts of them as a basis for discussion in your local parent support group. You may want to share some of the information with professionals working with your child.

When you have finished reading the chapters and doing the exercises, you should know more about the impact of emotional handicaps on a family, the legal bases for help, and the types of mental health services that are or should be available. For further information, consult the references/bibliographies at the end of each chapter.

Reading this handbook can be the beginning of your growing understanding of what can be done to help children with emotional handicaps. We hope you will want to learn more and that you will join with other parents to advocate for emotionally disturbed children and youth.

CHAPTER ONE: FEELINGS COME FIRST

SECTION ONE: UNUSUAL BEHAVIOR

Parents assume that their children are normal until the child behaves so differently that his or her unusual behavior cannot be ignored. As one father explained:

> *We thought Molly was a normal kid because we just didn't know any better. She was our first one. When she didn't sleep at night, we tried one thing after another--reading to her, rocking her to sleep, ignoring her, punishing her, even giving her cough medicine. Nothing worked.*
>
> *Daytimes weren't so good either. When I was at work, my wife couldn't control her at all. She was so destructive. Not just getting into things, but actually destroying things and not seeming to care when we were upset.*
>
> *When Molly turned three and neither one of us had had any sleep for weeks on end, we decided we just had to get some help. This couldn't be normal.*

According to Henry Reinert, author of *Children in Conflict*, there are four general types of behavior which parents come to recognize as unusual:

1. **ACTING-OUT BEHAVIOR** (self-abusive, aggressive, violent, disruptive, cruel);
2. **WITHDRAWING BEHAVIOR** (absence of speech, regressing to babyhood, fears, depression, avoiding social contact);
3. **DEFENSIVE BEHAVIOR** (lying, cheating, manipulating others, avoiding others);
4. **DISORGANIZED BEHAVIOR** (out-of-touch with reality, assuming multiple personalities, hallucinating).

A child may exhibit just one of these types of behavior or some combination of two or more of them.

Some abnormal behaviors are more severe than others. In fact, behavior problems range from mild problems which are resolved with short-term assistance, to moderate problems requiring intensive help, to severe problems demanding long-term care and specialized treatment.

CAUSES DIFFICULT TO FIND

When a child behaves in unusual ways, it is difficult to say whether there is something wrong with the child, or whether the child is reacting defensively toward abuse, neglect, violence, or other unfavorable circumstances in his or her environment. Is there a genetic, biological or neurological cause for the child's behavior? Or, is the child's behavior a result of imitating poor models? Is the child reacting to physical or emotional deprivation or merely behaving the way his own body and mind force him to behave?

The causes of emotional and/or behavioral disturbances are not as clearly know as in the case of an infectious disease in which a particular bacterium is the known cause. In the majority of mental health professional schools, the most recent and well-received model used to explain the origin of mental disorders is the bio-psycho-social model. (Numerous other models, although less popular, are still used. See pages 24 and 25 for a further discussion of these models.)

This model implies that mental disorders are due to a combination of biological, psychological, and environmental factors. This model does not explain which factors are the most responsible or prominent in the etiology (or cause) of emotional and/or behavioral disturbances. The most important aspect of this model is the premise that more than one factor is involved. Biological factors may include an individual's genetic makeup, brain chemistry, head injuries, brain infections (meningitis and encephalitis, for example), serious nutritional deficiencies, and toxic substances such as lead. The area of psychological factors may include problems with intelligence, reasoning ability, self esteem, and motivation. Environmental or social factors related to peer relations, culture, economics, school problems, and family problems may also contribute to emotional problems. When children belong to a minority group whether by virtue of culture, social class, race, religion, family lifestyle or for other reasons, it is important that this be considered in the assessment of the child's behavior and the family situation, as well as in subsequent treatment.

Parents often face two problems: (1) accepting the fact that their child is not normal, and (2) dealing with uncertainty about why the child behaves strangely. The one certainty parents have is that their child has a serious problem which affects the family deeply.

SECTION TWO: IMPACT ON THE FAMILY

PARENTS' REACTIONS

LOSS OF SELF-ESTEEM. No parent of a child who is emotionally disturbed is prepared for the experience. No matter how self-confident or outwardly successful parents may be, the revelation that their child is disturbed can be devastating to their self-worth. As one mother put it:

> *What did we do wrong? No one in our family has ever been mentally ill. Our other kids are normal. We treated them all the same. Why is this kid screwed up? What's the matter with us?*

Sometimes parents reason: if we have a "defective" child, we must be "defective" people. Even though parents are often not responsible for their children's emotional handicaps, no amount of reassurance eases the parents' sense of failure and loss.

SHAME AND GUILT. Because of their own emotional vulnerability, parents often willingly accept the blame for causing their children's illnesses. They feel ashamed that their ability to love and discipline their child appears to have failed so completely. They wonder: Why do some parents seem to raise "model children" so easily, while we have tried hard with our child and gotten nowhere?

Sometimes parents blame each other. Deep-seated resentments in a marriage come to the surface. Dislike of in-laws becomes magnified. Spouses blame each other's families for having "defective genes." Sometimes parents' religious backgrounds may cause them to feel that their child's behavior is the result of "God's judgment" on the family.

Feelings of shame and guilt come from the parents' strong sense of responsibility and desire to protect and nurture their child. Those feelings also come from a loss of pride. Their child has not turned out the way they expected. Their best efforts appear to have resulted in failure:

> *We had dreamed of having a little boy. At first, when we adopted Mel he seemed so bright and quick--just the child we wanted. Then we began to notice the odd behavior, the uncontrolled rages, the mean, belligerent remarks--even to total strangers. We were stunned. Our dream had become a nightmare.*

SORROW. Sorrow is a natural response to the "death" of the dreams and fantasies that parents have had for their child. Parents need a period to mourn the loss of the perfect child they had in mind. Parents also mourn because they see their child suffering and causing others to suffer.

DENIAL. On the other hand, some parents deny their child has a problem even in the face of abundant evidence of an emotional disturbance. They pretend not to notice the child's strange behavior. They ignore temper outbursts, destructive behavior or episodes of lying and cheating--minimizing their importance or pretending they never happened. One mother said,

> *I knew he was gradually breaking all of the toys and furniture in his room, but I just kept cleaning up and hauling away the broken pieces as though nothing had happened. Disciplining him seemed to be such an effort and did no good. Soon his room was bare and scarred. I was ashamed to go in.*

WITHDRAWAL. When parents begin to realize that their child is emotionally disturbed, they sometimes instinctively withdraw from their normal associations with other people. Emotional disturbance is difficult to explain. Many parents avoid contact with other people because they fear what others will say, or they think no one else can possibly understand their problems.

ANGER. Other parents become angry and lash out at each other, and at family and friends. "Why us?" they ask. "We have done nothing to deserve this." They are angry because their child is the victim of a condition which is difficult to diagnose and treat. They are angry, too, because they cannot find services for their child, because laws and interagency squabbles interfere with getting help, and because family and friends are too fearful and uncomfortable to offer comfort and understanding.

DEPRESSION. The responsibility for the care and nurturing of a child with an emotional handicap sometimes overwhelms even the most steady parent. Depression hits, especially on those days when the child has been the most out of control or the most withdrawn. The long haul, the up-hill fight, of raising such a child sometimes appears to be too great a responsibility and the parent gives in to discouragement and depression.

FEAR. Many times parents have difficulty convincing others of the seriousness of their child's problems. They fear that their child will not get help in time--that he or she might harm someone or do serious damage before treatment is available. Parents fear the future. They have few guidelines to tell them how to behave; therefore, they have many questions in their minds: How will we care for this child? What does the future hold? Will he/she get worse? Can we afford treatment? There are many unknowns to face, and parents fear they will not have adequate personal resources to manage all that may be in their child's future.

AMBIVALENCE. For many parents, their most frightening emotions are their feelings toward their handicapped child. On the one hand, they love their child and want to help him or her. But they resent the child's behavior--the burden it places on the family, the pain it causes everyone who knows the child. Parents may experience feelings of rejection and anger toward the child, and then feel guilty for having those negative feelings. One father tearfully expressed his mixed feelings this way:

> *I found myself hating my own kid, wishing he had never been born. I saw what he was doing to my wife, the way my daughter hid from him-- I knew he was destroying us and I hated him for it. Yet, deep inside I loved him so strongly. He was ours and meant so much to us. How could I hate my own son?*

CONFUSION. Perhaps the most common feeling experienced by parents of emotionally disturbed children is a sense of confusion or loss of control. Because the discovery of serious problems in a child always comes as a shock, parents are often overwhelmed by a rush of conflicting feelings. They want to love and protect their child, but at the same time their minds are flooded with fears, doubts, guilt, anger, sorrow, and shame. Their lives seem suddenly out of control because their child's behavior is so unpredictable and so different from what they expected.

Many parents report that in their confused state they are unable to grasp information or to process what is going on around them. Their moods swing wildly from hopefulness to depression. They run around trying to do one thing after another, never finishing one task before starting another. Or they stop being active and withdraw, and sit for hours unable to move or function. Their feelings change from moment to moment.

For some parents, loss of control over their personal lives leaves them with a sense of powerlessness. While they realize the need to be strong and supportive for their child's sake, they are uncertain about what to do next.

OTHER FAMILY MEMBERS' REACTIONS

The brothers and sisters of children who are emotionally disturbed can be deeply affected by the behavior of their brother or sister. Siblings sometimes become angry because their handicapped brother or sister is destructive and hurts them or ruins their things. Sometimes brothers and sisters are embarrassed by a sibling's odd behavior, or they are jealous because that sibling receives so much of their parents' attention. While it is easy to have sympathy for a child who is physically ill or disabled, it is not as easy to feel sympathetic toward a brother or sister who behaves oddly.

Grandparents and other adult relatives, depending on the amount of exposure they have to the child with emotional disturbance, may experience many of the same emotions parents feel. If they live at a great distance, they may also experience a sense of helplessness because they cannot do anything on a daily basis to assist the family. Particularly in cultures and ethnic groups that rely on extended family or multiple caregivers; relatives and grandparents may hold the parents responsible for the child's problem, out of love for the child.

SECTION THREE: COPING WITH A HANDICAPPED CHILD

Parents are amazingly resilient. They hope when it is unreasonable to hope; they bounce back when no one expects that they will. Even the formidable problems associated with emotional handicaps do not stop parents from loving their children and doing what they have to do to sustain their family and help the child.

COMING TO TERMS WITH FEELINGS

Parents and family members of children who may have an emotional handicap have a particularly difficult challenge. It is natural for them to begin to think they are the disturbed ones, especially when blame is heaped upon them by "professional experts." As one father put it:

> *Everywhere we turned someone had something negative to say about the way we raised our son. They questioned us about everything we did. They blamed us for Ron's crazy behavior. We were exhausted and began to think they were right. Maybe we were crazy!*

For minority families, expressing this dilemma to professional experts, particularly those of the dominant culture, may be demoralizing, inappropriate, or stigmatizing. Especially in situations where their child gets involved with the juvenile justice system, parents may feel frightened and overwhelmed. Families may want to see experts accompanied by an advocate or other ally with experience in similar situations.

When parents must deal on a daily basis with the difficult behavior of such a child, they are under tremendous strain. They have all the responsibilities other parents have, plus the added burden of dealing with behaviors that are extreme and unpredictable. It is normal and expected that these parents will experience strong emotional reactions to their situation. Their emotions are a part of the human process of facing the problems of having a handicapped child.

ADVICE FROM OTHER PARENTS

Parents who have coped with their own feelings have strong advice for other parents who are just beginning the process:

1. Refuse to feel guilty. No parent or family is perfect. Accept the fact that you have done your best. The needs of your child are beyond the usual and beyond what you alone can provide. That is okay. To help your child, you have to refuse to be weighed down by guilt. So what if you are "guilty"? Does it help? What matters are the things that can be done now for the child and for you.

If you cannot shed the guilt on your own, get some professional help for yourself. The first battle is accepting yourself.

2. Be realistic about what you can and cannot do. No one who understands your situation expects you to be supermom or dad. Sometimes, professionals do have high expectations for you and your family, and you will have to help them see your family situation more realistically. There are legitimate limits to how much time, energy and emotional tolerance you have for your handicapped child. You must assess your limitations, accept them, and insist that others accept them. This is a tall order, but it is also the only way that you can continue to be of use to your child.

   When you know your limitations and have accepted them, you are better able to accept the help professionals can provide. It may be very tough, for example, to accept the fact that a foster parent or a special education teacher is more effective with your child than you are, but if they truly are more effective, you certainly do not want to be the one standing in the way of your child's getting the help he or she needs.

3. Get some support. Being the parent of a child who is emotionally disturbed does set you apart. It can be lonely. You need emotional support for yourself. Some parents find that support in a close friend or family member who provides unconditional love and acceptance. Others turn to church or counseling groups. Many parents whose children have emotional disturbances find comfort in making connections with other parents whose children have similar handicaps. In any case, you must find help and support from at least one sympathetic adult.

   You need what Susan Duffy calls "emotional information"; that is, to be told over and over again by someone you trust that your feelings are normal and that you are a valuable, worthwhile person. The time and emotional energy you give your child must be replenished so that you can go on giving.

ACCEPTING THE CHILD

At some point, you have to make a conscious effort to see your child as he or she is--without excuses or cover-ups. Once you have this clear picture in mind, you have to accept what you see. This is your child--a child first, a person you love simply because he or she is there.

You must then acknowledge your child's disability. That does not mean you have to like it. Emotional disturbance is not something you would choose for your child. But it is a real, undeniable fact--a problem to be faced squarely and dealt with. A young mother explained how she came to terms with her child this way:

> *For a long time I just hated Lonnie. I hated him for ruining my life, for causing the divorce, for being around at all. I could hardly look at him sometimes because he seemed to be the source of all my problems.*
>
> *Then I looked again--really looked--and saw the lost, frail child who had been there all along. Lonnie did not choose to be sick. At that moment I loved him so much and felt so bad for all that I had been thinking.*

TAKING ACTION

Once you have faced the problem squarely, you are ready to take action. Experienced parents who have been successful in helping their children suggest doing the following things:

1. Be specific about the problem. When you seek help from professionals, clearly identify the problem. Such statements as "Johnny is impossible" or "Mary never minds me" does not give a complete picture of the kinds of behavior which have been troublesome. The professionals you consult may not be convinced that there is a problem unless you can give them specific information about:

   a) the troublesome behaviors you have observed;
   b) the age-appropriateness of these behaviors;
   c) the severity of the problem or level of dysfunction;
   d) the frequency of the behaviors;
   e) the duration of the problem; and
   f) the type of situation in which the behavior occurs.

   The need for specificity is particularly important when the professional and family seeking help are not from the same class, or culture. Sometimes languages and dialects, behavioral mannerisms, styles of interaction, and life circumstances of people from one background can be confusing to those of another group. Therefore, for example, language which is not understood may be interpreted as disturbances in thinking; an unwillingness to open up or establish eye contact may be understood as social withdrawal; or, unfamiliar gestures or mannerisms may be seen as strange behavior.

   Families may want to get help in expressing their concerns and observations so they can feel more comfortable in discussing both important and personal family information. Families may want to go over what they would like to say to their clinician with someone they trust who has skills in communicating cross culturally and in working with social service agencies. Such people may include extended family, clergy, educators, family doctors, child advocacy groups, or parent support groups. This will not only help in insuring that your concerns will be more easily understood, but may generally make such interaction less stressful.

2. Know what you are talking about. Keep records of your observations of your child. Keep copies of all the information you receive from

individuals working with your child. Be prepared to present your information in a clear, organized fashion with facts to back up your claims.

3. Keep talking to people. The mental health field is constantly in flux. New programs and new ideas spring up overnight. It is wise to maintain a healthy skepticism about much of what you hear and read, but it is also important to remain alert. One of these new programs or ideas may fit your child's case and prove to be very useful.

4. Research the problem on your own. There is no reason why you cannot research your child's problems on your own. Go to the library. Consult the scientific literature. Look up terms you do not understand. Because you are likely to be persistent, you may run across an idea which professionals working with your child have overlooked or not previously discussed with you. It would be wise to share it with the professional.

5. Consider what you are told in relation to what you have observed. Don't accept a diagnosis or suggestion for treatment from professionals unless it matches what you know from experience about your child. You are with the child more than anyone else. Your observations are certainly valid pieces of information. If you doubt a professional's diagnosis and/or suggestions seek another opinion.

6. Think it through. Take time for yourself for quiet reflection on your child's problems and the solutions which appear to be available. Do not be forced into quick decisions in the doctor's office or at a school conference, if you are not ready to decide. Your ideas and concerns should be incorporated into the treatment plan for your child.

7. Find the right specialists. In the mental health field there are a number of types of professionals. In addition, this field seems to attract a variety of unqualified practitioners who attempt to take advantage of vulnerable parents. It is critical to choose the right specialist to diagnose and treat your child. See Chapter Two of this handbook for information about mental health professionals.

8. Check out the professionals. Be sure to make inquiries about the professional's credentials. In some states it is possible to advertise yourself as a therapist without having any particular training or license. Consult the respective professional societies and the state licensure boards for social workers, psychologists and therapists to make sure that the professional you are seeing has appropriate training. Members of minority families and those of non-mainstream lifestyles might want to look for professionals who have experience with similar families. You may also want to ask professionals directly if they feel that they can work effectively with your family.

9. Trust your instincts. After being through so much, you may begin to doubt your own wisdom, but do not give up on yourself. Parents are often right

about children's needs and should advocate so that their opinions are heard.

10. Put the child first. Once therapy and treatment have begin, it is easy to get caught up in details and forget the child. No matter what program you are following, do not lose sight of the child. Spend time on family relationships and work through problems with the child's needs foremost in your mind.

ACCEPTING THE HANDICAP

Determined parents can be outstanding detectives, seeking out information and assistance for their child, but eventually there comes a time when they must decide to stop searching and accept those aspects of the child's emotional handicap which cannot be changed. In some cases it may be necessary to set aside hopes for the "big cure" and become content with more modest gains and smaller steps forward. With some emotional disturbances, a child may have to be on medication for the rest of his or her life. In other cases, the individual may always have some emotional limitations or may need long-term care and therapy. Accepting these limitations helps parents to shift emphasis away from the search for cures and toward realistic goals for treatment and daily living.

The process of adjusting to living with a handicapped child requires a great deal of hard work, soul-searching and individual development to meet challenges which arise. Parenthood does not automatically confer superhuman strength and abilities. Parents grow into the role, summoning the resources they need from family, friends, and religion or personal philosophy. Some people do not have the resources to make the necesssary adjustments; others must grow into the role at a very gradual pace. But most parents, in their individual ways, come to accept their role as a parent whose child has special needs.

BECOMING AN ADVOCATE

During the time when parents are coming to terms with their child and his or her disability, they tend to look inward and to be concerned with their family and their individual needs. Gradually, as coping with the situation becomes easier, parents can begin to look outward again. In the process of coping with their own child, parents learn many skills which they can use in advocating, not just for themselves, but also for others.

There is a need at many different levels for parents to be advocates for their child and for all children with emotional disturbances in their school district, home community, state and nation. Historically, mental health services have developed as a result of parents, relatives and friends of the disabled working and pushing for what they needed. Improved services have come about, not so much because of public sympathy or concern for the mentally ill, but because parents and others have applied enough pressure. No matter how small, every effort to affect needed change moves the system one step further along the road toward richer, more productive lives for children and youth with emotional disturbances.

There are numerous groups and organizations that can help you advocate for your child. These groups include the National Alliance for the Mentally Ill (NAMI), the National Mental Health Association, and the Association for Retarded Citizens (ARC), which are all national organizations that have local chapters and have demonstrated good advocacy skills. The American Civil Liberties Union (ACLU) and the National Organization for Women (NOW) may also help you learn about or devise advocacy strategies to protect your child's or your family's rights. The National Urban League, the National Association for the Advancement of Colored People (NAACP), the League of United Latin American Citizens (LULAC), the G.I. Forum, the National Congress of American Indians, and regional or local Native American tribal organizations may also help. In some instances mental health agencies or other social service organizations provide information and referral (I&R) services that may identify advocacy and support groups. Families can also identify support closer to home in the form of religious, community based, civil rights, and legal aid organizations.

There is much that still needs to be done. Many young people with serious disturbances do not get any services. Frequently, there are legal obstacles to receiving the services which are available. Support services to relieve the stress on parents are lacking in most parts of the United States. In many cases, we know what services would be beneficial, but we have not allocated the resources to provide those services. One resource that describes what a system of care for children with serious emotional disorders should look like is *A System of Care for Severely Emotionally Disturbed Children & Youth* by Stroul and Friedman (1986). When faced with the lack of services, one father put it bluntly:

> *It made me so damned mad that my daughter needed help and there just wasn't any available at any price. The only way to get her treatment was to give her up to the state and I wasn't about to do that.*
>
> *Getting mad made me see that something had to be done and that I was the guy who better do it. No politician was going to care about my child unless I made him do it.*

Parents can make a difference in the mental health system. When you are ready to reach out, there are other parents who will join you in efforts to inform the public and to influence political and social decision-makers. As an informed parent, you can take control of your own situation and do a great deal to assist your child and others in receiving appropriate treatment, education and support.

EXERCISES

QUESTIONS

The following exercises provide an opportunity for you to think about what you have read. The page numbers for each exercise indicate the section of the text on which the questions are based. Answers for the exercises are on page 18.20

EXERCISE Section 1 Number 1 (pp. 3-4)

Determining whether a child is emotionally disturbed depends on three factors:

1. How severe the child's inappropriate behavior is;
2. How long the child has acted strangely; and
3. In what situations the behavior occurs.

Based on these three factors--severity, duration, and appropriateness for the situation--indicate which of the following children displays behavior which you think possibly reflects emotional disturbance.

YES NO 1. STEVE broke down in tears several times in his third grade class during the week following his father's death.

YES NO 2. Every afternoon alone in her room, sixteen-year old MARY sucks her thumb and stares into space. She can frequently be heard talking to herself and humming a tune.

YES NO 3. Eleven-year old SARA flies into a rage when a sixth grade classmate brushes past her in the hall. Sara shouts an obscenity, picks up a nearby wastebasket, and hurls it at the lockers.

YES NO 4. MIKE, who is three, throws himself on the floor and has a tantrum when his parents tell him no.

YES NO 5. Four-year old SUSIE does not talk. At preschool, she rocks quietly and spins the knobs on the toy stove. She grabs snacks when they are offered and often steals food from the other children.

EXERCISE Section 1 Number 2 (pp. 3-4)

Read the following case studies and decide which type of behavior the child is displaying: acting-out, withdrawing, defensive, disorganized, normal.

________ 1. A shy girl, SHANNON, seldom speaks up for herself. Frequently, others answer before she is ready to respond. As the number of her failures has increased, Shannon has begun to doubt her ability to succeed in any situation. Gradually, Shannon has refused to try any new activities, offering the excuse of not feeling well. Eventually, she adopted the attitude of an invalid and says she is too sick to participate in any activity.

________ 2. KENNY says he does not know his name. He does not know who he is. Though he is a good-looking ten-year-old with an excellent vocabulary, his conversation often does not make sense. He appears to be talking to people who are not present. He screams for no apparent reason. At night, he seldom sleeps more than an hour or two. He wanders through the house, opening and closing doors and calling out.

________ 3. MARK, who is three, has begun to bite his playmates at preschool. If another child takes a toy from him, he will bite that child. He seems unconcerned if the other child cries, but responds if the teacher tells him "No."

________ 4. SEAN makes up stories about his family which he tells his fifth grade class each day. Even when other students openly make fun of his obvious fantasies, Sean persists in telling his stories. The teacher has confronted Sean about his lies, but he earnestly denies that the stories are untrue. Lately, he has begun to draw fantastic pictures of his family members suffering horrible tortures. Other children are shocked by the drawings, but Sean does not seem to notice.

________ 5. MARILYN loudly demands the teacher's attention. She pushes her way to the head of the line whenever her second grade class leaves the room. If another child reminds Marilyn to wait her turn, Marilyn strikes out, often knocking other children to the ground. Sometimes Marilyn locks herself in the bathroom stall and defecates on the floor. No amount of scolding or punishment changes her behavior. She appears to enjoy hurting others and doing shocking things.

EXERCISE Section 3 Number 1 (pp. 8-13)

The following statement describes one person's attitude toward being a parent whose child has special needs. Read through the statement and respond from your own experience to the questions that follow. There are no right or wrong answers. As a result of thinking about your answers, you should develop some insight into your own attitudes.

> Parents of special children are special people. They are uniquely chosen by God to have disabled children because they are *uniquely gifted*, capable of incredible love and unstinting dedication.

1. Do you see yourself as "uniquely gifted" to care for a child with special needs? Why or why not?

2. Do you think that parents of special children are "special people"? Why or why not?

EXERCISE Section 3 Number 2 (pp. 8-13)

Agree or disagree with the following statements:

________ 1. For parents whose children are emotionally disturbed (ED), "the first battle is accepting yourself."

________ 2. Parents need "emotional information" about themselves.

________ 3. You have to make a conscious effort to see your child as he or she is.

________ 4. It is wise to maintain a healthy skepticism about much of what you hear and read in the mental health field.

________ 5. There is no reason why parents, on their own, cannot research their child's problems.

________ 6. Parents should not accept a diagnosis or suggestion for treatment from professionals unless it matches what they know from experience about their child.

________ 7. All parents have the resources to deal with a child who has an emotional disturbance.

________ 8. Feelings of guilt are normal for parents whose children have emotional handicaps.

________ 9. Knowing the causes of emotional problems leads directly to solving those problems.

________ 10. Parents are good observers of their children's behavior.

EXERCISE Section 3 Number 3 (pp. 8-13)

Complete the following sentences in your own words.

1. I see myself becoming an advocate for ED services when. . .

2. What I need most as a parent is. . .

ANSWERS

HOW DID YOU DO? EXERCISE 1.1 (p. 15)

1.	No	Steve's behavior probably does not reflect an emotional problem. Given his situation (father's recent death) and his age, his behavior is normal and to be expected.
2.	Yes	Mary's behavior indicates a need for further evaluation. A sixteen year old who sucks her thumb (very inappropriate for her age) and spends a great deal of time alone may indeed be experiencing emotional problems.
3.	Yes	Sara's reaction to a casual bump in the hallway appears to be extreme for the situation. Further investigation of her behavior patterns appears to be appropriate.
4.	No	Unless Mike has frequent uncontrollable tantrums and/or other problematic symptoms, his behavior seems to be normal for his age.
5.	Yes	Susie's behavior is of real concern. She displays a long-term pattern of not talking and associating with others. Her aggression at snack-time is extreme for her age. Susie probably should be evaluated for behavior problems.

HOW DID YOU DO? EXERCISE 1.2 (p. 16)

1. Shannon is displaying *withdrawing* behavior.
2. Kenny is displaying *disorganized* behavior.
3. Mark is displaying *normal* behavior.
4. Sean is displaying *defensive* behavior.
5. Marilyn is displaying *acting-out* behavior.

HOW DID YOU DO? EXERCISES 3.1 (p. 17), 3.2 (p. 18) and 3.3 (p.19)

Answers to these questions will vary.

REFERENCES/BIBLIOGRAPHY

Appolloni, T. (1985). Effective advocacy: How to be a winner. *The Exceptional Parent*, 15, 14-19.

Bernheim, K.F., Levine, R.J., & Beale, C.T. (1982). *The caring family: Living with chronic mental illness.* Chicago, IL: Contemporary Books, Inc.

Binkard, B., Goldberg, M. & Goldberg, P.F. (1984). *A guidebook for parents of children with emotional disorders.* Minneapolis, MN: Parent Advocacy Coalition for Educational Rights, PACER Center, Inc.

Buscaglia, L. (1975). *The disabled and their parents: A counseling challenge.* Thorofare, NJ: SLACK, Inc.

DeLuca, K.D. & Salerna, S.C. (1984). *Helping professionals connect with families with handicapped children.* Springfield, IL: Charles C. Thomas.

Duffy, S. et al. (1984). *Acceptance is only the first battle.* Montana University Affiliated Program, University of Montana, Missoula, MT.

Featherstone, H. (1981). *A difference in the family. Living with a disabled child.* New York: Penguin Books.

Fernandez. H. (1980). *The child advocacy handbook.* New York: Pilgrim Press.

Knitzer, J. (1982). *Unclaimed children: The failure of public responsibility to children and adolescents in need of mental health services.* Children's Defense Fund, 122 "C" Street, N.W., Washington, D.C. 20001.

Reinert, H.R. (1976). *Children in conflict.* St. Louis, MO: C.V. Mosby Co.

Stroul, B.A. & Friedman, R.M. (1986). *A system of care for severely emotionally disturbed children & youth.* National Institute of Mental Health, CASSP Technical Assistance Center, 3800 Reservoir Road, N.W., Washington, D.C. 20007.

Turnbull, H.R. III & Turnbull, A.P. (1985). *Parents speak out: Then and now.* (2nd ed.). Columbus, OH: Charles E. Merrill Publishing Company.

Vine, P. (1982). *Families in pain: Children, siblings, spouses, and parents of the mentally ill speak out.* New York: Pantheon Books.

CHAPTER TWO: FINDING SOME HELP

Finding help for a child with an emotional disturbance can be a difficult task for a parent. Many times parents find themselves getting the runaround from a variety of agencies. One mother described her dilemma this way:

> *We called the psychiatrist and the social worker and said, "What do we do? Where do we go for help?" They had no idea where to go or what to do. Their only solution was to "Hang in there. Things will get better." Things weren't getting any better. Tommy was completely out of control. He heard voices. The voices told him to kill people. He was stealing. He couldn't function at school. He was failing all of his classes. We called the school again and asked, "What can we do as parents to get some help for Tommy?" Their response was, "We don't know. There is nothing we can tell you. There's no place to go. You're a parent, so you deal with it."*

Like this mother, many parents are left alone to find help the best way they can. For them, the mental health field is a confusing array of theories, varieties of therapy, and types of services. This chapter is meant to assist parents as they search for general information about emotional disturbance and about services and therapies available. While this chapter is introductory in nature, it does contain references and a bibliography with information about materials that go into greater depth on mental health subjects.

SECTION ONE: WHAT IS PSYCHOTHERAPY?

Psychotherapy is a broad term meaning the treatment of mental or emotional disorders. Sometimes psychotherapy is confused with the more specific term psychoanalysis, referring to a treatment model based on the theory that mental disorders are caused by significant emotional events in the individual's past. Psychoanalytic treatment involves exploration of the patient's past to find the causes for current behavior.

Psychoanalytic therapy is, however, just one form of psychotherapy. Other therapies based on different models include: non-directive, supportive therapy; confrontive therapy; behavior modification; humanistic therapy; family and milieu therapy; and many more. There are numerous treatments used in the field of mental health. Well-trained clinicians often use several of these models with the same client.

MODELS TO EXPLAIN EMOTIONAL DISTURBANCES

The models included here represent a partial list of the models currently used to explain emotional disturbances, or provide treatment for emotional disorders.

BEHAVIORAL MODEL. Behavioral theory is based on the concept that all behavior, including inappropriate behavior, is learned. Behaviorists are not interested in finding the "causes" of emotional disturbance. Rather, their emphasis is upon bringing about positive changes in the patient's behaviors. Behavioral therapists try to determine what is supporting or maintaining behaviors, and then try to change those behaviors by providing positive reinforcement for desirable behaviors and, when necessary, ignoring (called extinguishing) or using negative reinforcement for undesirable behaviors.

BIOLOGICAL MODEL. In the biological model, it is assumed that the cause of emotional disturbance is a physical problem. The basis of the problem may be primarily genetic, nutritional, medical (physical illness or poison), or due to early life injuries. The therapy in the biological model often involves medication therapy and/or changing the patient's physical environment (e.g. by removing lead-containing paints or other toxic substances in the environment).

BIO-PSYCHO-SOCIAL MODEL. This model implies that mental disorders are due to a combination of biological, psychological, and social or environmental factors. See page four of the handbook for a further discussion of this model.

ECOLOGICAL MODEL. In ecological theory, the therapist assumes that the causes of the patient's problems can be found in the interactions between the individual and his or her environment. Treatment in this model involves simultaneous intervention with the individual and with his or her surroundings. Family therapy, which involves intervention with family members and family interactions as well as with the individual, is an example of an ecological therapy.

INTERACTIVE MODEL. A variation of the biological model is the interactive model which suggests that emotional disturbance is the result of a complex set of interactions between a basic physical abnormality and environmental and social "triggers" which activate or aggravate symptoms of emotional disturbance.

Treatment based on an interactive model may involve a combination of strategies, including drug therapy, behavior modification techniques, counseling, and family therapy.

PSYCHOANALYTIC MODEL. Interventions based on psychoanalytic theory treat mental and emotional disorders by analyzing the facts of the patient's mental life. The causes of illness are assumed to be the result of psychological problems or conflicts which began sometime in the patient's past. Psychoanalytic therapy helps the patient by providing insight into present behavior through an analysis of conflicts in the individual's past.

There are a number of significant types of psychoanalysis, including the most famous and influential--Freudian theory--as well as other theories such as Rogerian client-centered theory, Ellis' rational/emotive system, Schultz and Burton's encounter movement, Glasser's reality therapy, Jungian analysis and Adlerian therapy. Some therapists adhere to just one of these theories, while others draw on ideas and techniques from a number of perspectives.

PSYCHOANALYTIC THERAPY FOR YOUNG CHILDREN. Most models of psychotherapy are set up for adults. They rely heavily on the adult's ability to talk about problems and describe and analyze behavior. Some of these adult models work successfully with teenagers, but most are not appropriate for young children who do not have the ability to verbalize their feelings.

PLAY THERAPY has been developed as a type of psychotherapy particularly suited for use with young children. The purpose of play therapy is to unfold the child's inner world without relying on verbalization. The therapist who uses this method of treatment observes the child in structured play situations and notes the child's reactions as various situations are presented. The therapist's role is to help the child gain insight into his or her behavior, to identify appropriate limits on behavior, and to provide the child with the ability to solve problems.

SECTION TWO: COMMON CONDITIONS EXHIBITED BY CHILDREN AND YOUTH WITH SEVERE EMOTIONAL DISTURBANCE

The American Psychiatric Association has developed a classification system for mental illnesses. The latest revision of this classification system, the *Diagnostic and Statistical Manual of Mental Disorders (3rd Ed. Revised)* (DSM- III(R)), includes a category of disorders first evident in infancy, childhood or adolescence. This manual is the most frequently used diagnostic classification system in clinical settings. The names used in this manual are not as frequently used in other settings, such as schools. Below are descriptions from the DSM-III(R) of some of the mental disorders with brief, identifying definitions. For more information about these and other disorders, consult the references/bibliography pages at the end of this chapter.

DISRUPTIVE BEHAVIOR DISORDERS

Children with these disorders exhibit socially disruptive behavior, i.e. behavior that interferes with social situations, such as the classroom, playground situation and family activities.

ATTENTION-DEFICIT HYPERACTIVITY DISORDER. Attention-deficit Hyperactivity Disorder (ADHD) is a condition characterized by a failure to remain attentive in various situations, especially in the school and home. Current thinking emphasizes that the causes of ADHD are likely to be biological. The most effective treatment for this disorder appears to be a combination of psychotherapy and a stimulant medication such as Dexedrine, Ritalin or Cylert. (In previous editions of the DSM, this disorder has been called Attention Deficit Disorder (ADD).)

CONDUCT DISORDER. The term conduct disorder is used to refer to young persons who have shown a repetitive and persistent pattern of conduct which violates either the basic rights of others or age-appropriate social norms or rules.

Children with "unsocialized conduct disorders" are described as failing to establish a normal degree of affection, empathy, or bond with others. They may have superficial peer relationships, be egocentric and manipulative, lack concern for the welfare of others and be without guilt or remorse.

The more socialized types of young persons with conduct disorders are described as being capable of attachment to others, such as to peers, but they resemble the undersocialized types by being callous or manipulative toward persons to whom they are not emotionally attached.

Children with aggressive conduct disorders are characterized by physical violence against others, ranging from vandalism, firesetting and burglary to rape and murder. The non-aggressive child with a conduct disorder may break rules at home or at school and may be truant, a substance abuser, or a runaway.

OPPOSITIONAL DISORDER. Children with an oppositional disorder display their aggressiveness by patterns of obstinate, but generally passive behavior. They appear to be conforming, but they continually provoke adults or other children.

By the use of negativism, stubbornness, dawdling, procrastination, and other measures, they covertly show their underlying aggressiveness.

ANXIETY DISORDERS OF CHILDHOOD OR ADOLESCENCE

These disorders include those in which anxiety is the most prominent clinical feature. In some disorders, the anxiety is focused on specific situations; in others, there is generalized anxiety. Anxiety disorders refer to any of a number of exaggerated or inappropriate responses--affective (emotions), cognitive (thinking), motor (movement) or physiological (physical symptoms)--to the perception of external or internal danger.

SEPARATION ANXIETY. School phobia is a form of separation anxiety brought about by the necessity of leaving home and family members to attend school. It is usually a situational problem, but can be a serious psychiatric emergency if not dealt with when it first occurs. When children with school phobia refuse to go to school, they may panic unless permitted to stay at home. Often, the longer the children are permitted to stay out of school, the more severe are their social and educational impairments.

AVOIDANT DISORDER. Children and adolescents with avoidant disorders timidly avoid the establishment of new interpersonal contacts or ordinary relationships with strangers to an extent that there is noticeable interference with development of peer relationships and general social functioning. On the other hand, such children may enjoy relationships at home or with familiar persons and may seek new social relationships when non-threatening conditions exist.

OVERANXIOUS DISORDER. Children with this disorder have diffuse fears and worries that cannot be traced to specific problems or stresses. They worry excessively about examinations, potential injuries, friendships or group acceptance. Their anxiety may be expressed in various physiological symptoms such as headaches, respiratory distress and other recurring problems.

SIMPLE PHOBIA. Simple phobia is characterized by persistent irrational fears of a specific object, activity or situation (e.g., fear of heights, fear of airplanes, fear of crowds). Onset of phobias does not usually occur until late teens or early adulthood.

POST-TRAUMATIC STRESS DISORDER. This disorder can occur at any age, including childhood. It follows a psychologically distressing event that is outside the range of usual human experience. These include such experiences as child abuse, natural disasters, accidents, witnessing homicides, and war.

Re-experiencing the traumatic event is common. Young children may repeat the event in their play. Other symptoms include avoiding thoughts or feelings about the event and avoiding activities or situations that remind them of the event. They may feel detached from other people, take less pleasure in previously enjoyed activities, have trouble sleeping, have nightmares, and have difficulty concentrating. They may have various physical symptoms such as stomachaches and headaches. Young children may lose recently acquired developmental skills such as toilet training or language skills.

DEVELOPMENTAL DISORDERS

The essential feature of these disorders is that the primary disturbance is in the acquisition of motor, language, social, or cognitive skills. In **specific developmental disorder**, there is a delay in one area of skill development. **Pervasive developmental disorders** are distinguished from specific developmental disorders by the fact that multiple areas of development are affected in the former and thus are more *pervasive* in nature. The disorder described below is an example of a pervasive developmental disorder.

The term **pervasive developmental disorder** refers to a group of conditions marked by distortions, deviations and delays in the development of social and motor skills, language, attention, perception and reality testing.

AUTISTIC DISORDER. The onset of this disorder is during infancy or childhood; it is characterized by a failure to develop the usual relatedness to parents and other people. As infants, these children may lack a social smile, avoid eye contact, and fail to cuddle. These children also fail to develop normal language and may use non-verbal commands in place of speech. Some autistic children develop echolalia; that is, the meaningless repetition of what is said by others.

The activities and play schemes of the autistic child are rigid, repetitive, and lack variety. Autistic children may manifest over- or under-responsiveness to sensory stimuli, for example, to sound or pain.

The intellectual functioning of autistic children may range from profoundly retarded to normal levels. About 50 percent of autistic children are moderately, severely or profoundly retarded. Another 25 percent are mildly retarded and 25 percent have I.Q.'s of 70 or more.

MOOD DISORDERS

A mood disorder refers to a disturbance of mood and other symptoms that occur together for a minimal duration of time and are not due to other physical or mental illness.

BIPOLAR DISORDER. In this disorder, there is a distinct period during which the child's predominant mood is elevated, expansive or irritable, usually accompanied by a major depressive episode. The manic episode consists of an elevated mood that may be described as euphoric, unusually good, cheerful or high; but those who know the person well will recognize it as excessive. The disturbance is severe enough to impair normal activities and relations with others. Manic episodes usually begin suddenly with symptoms intensifying over a few days. Episodes may last from a few days to months.

Manic symptoms may include inflated self-esteem, decreased need for sleep while feeling full of energy, loud and rapid speech that is difficult to interrupt, continuous flow of speech with abrupt changes of topic, distractibility, restlessness, increased sociability; and disorganized, flamboyant or bizarre activities. There may be rapid shifts of elevated mood to anger or depression.

Depressive symptoms may include sadness, loss of interest in usual activities, and sleep and appetite disturbances. Older children may express feelings of worthlessness and guilt, difficulties in thinking or concentrating, and suicidal thoughts or recurring thoughts of death.

MAJOR DEPRESSIVE EPISODE. (Sometimes known as Childhood Depression). A type of mood disorder which may occur singly, recurrently, or accompany a manic episode as in a bipolar disorder. Like depressed adults, children may look sad, express hopelessness, lose interest in their usual activities, sleep more or less than previously, have a poor appetite, and say they feel tired. However, depression is sometimes manifested in different ways in children; for example, children may also be irritable, and fail to make expected weight gains.

Young children may feign illness, be hyperactive, cling to parents and refuse to go to school, and may express fears that their parents may die.

Older children may be sulky, refuse to cooperate in family and social activities, get into trouble at school, and may abuse alcohol or drugs. They may give less attention to their appearance, become negativistic, and express feelings of not being understood. They may become restless, grouchy or aggressive.

This disorder may also be strictly seasonal (October through November).

OTHER DISORDERS OF INFANCY, CHILDHOOD OR ADOLESCENCE

IDENTITY DISORDER. This disorder is characterized by a severe subjective distress regarding a youngster's inability to integrate various aspects of his or her acceptable sense of self. These aspects relate to career choice, friendship patterns, sexual orientation, religious identification, moral value systems, and group loyalties.

ADJUSTMENT DISORDER. Each one of this group of disorders is a *maladaptive reaction* to an identifiable source of stress (such as a death in the family or parents' divorce). Onset of symptoms is usually within three months of the source of stress; the duration of symptoms may be up to six months.

These disorders may seem to mimic normal psychological changes and concerns which occur during this stage of development. All adolescents experience some stress as they face the issues of establishing independence from family and personal identity in the adult world. Some adolescents, however, experience extreme anxiety, depression, eating and sleeping disorders, clinging to peers and parents, psychosomatic disorders, or impulsive acting out. These may be the *maladaptive reactions.*

Characteristics of these disorders may include:

1. Impairment in the normal level of social and educational functions;
2. A disturbance of mood;
3. A conduct disturbance; and/or
4. Physical symptoms which do not have a medical basis.

SCHIZOPHRENIA. Schizophrenia is a disorder in which there are characteristic disturbances in several areas including thought content, perception, affect (emotional) response, sense of self, relationship to the environment, and behavior. These symptoms often vary over time. In general, the term refers to a psychotic disorder characterized by loss of contact with environment and by disintegration of personality. Symptoms of the illness may include: hearing one's thoughts spoken aloud, auditory hallucinations that comment on the individual's behavior, imagined illnesses or pains, the experience of having one's thoughts controlled, the spreading of one's thoughts to others, delusions, and the experience of having one's actions controlled or influenced from the outside. The onset of schizophrenia usually occurs in young adulthood but symptoms can develop as early as childhood.

Editor's Note: On page four, the author noted that causes of emotional disturbances are difficult to find. Changes in our understanding of causes occur through research, and result in more appropriate treatment for specific disorders. The following section describes such changes that occured over a number of years related to one specific disorder, Autistic Disorder.

ARE AUTISTIC CHILDREN CONSIDERED SEVERELY EMOTIONALLY DISTURBED?

Autism has been recognized as a separate illness or condition for approximately 40 years. During this period, professionals' conceptions of autism have changed dramatically. When Leo Kanner first identified infantile autism in 1943, he regarded the autistic child's "inability to relate...in the ordinary way to people and situations from the beginning of life" to be the characteristic which distinguished autism from schizophrenia and other types of psychosis. Kanner considered autism to be a mental illness and suspected that, because autism had not been distinguished from schizophrenia and other mental disorders, it was actually a more common problem than previously suspected.

Despite Kanner's warnings, confusion in distinguishing between autism and schizophrenia continued. In 1952, psychotic reactions in children, meaning primarily autistic-like symptoms, were classified in the *Diagnostic and Statistical Manual of Mental Disorders-I* under "schizophrenic reaction, childhood type."

During the 1960's, English psychiatrists developed nine criteria for diagnosing psychosis in childhood. These nine points were very similar to the criteria Kanner had used for autism, resulting in confusion as to the difference between autism and childhood psychosis. Among professionals, an argument developed over whether autism was a separate mental illness or merely the early stages of psychosis or schizophrenia.

The causes of autism were as unclear as its definition. Kanner's original thought was that autism was a distinct illness caused by family interactions involving parents who lacked warmth and were preoccupied with intellectual abstractions. Kanner believed, however, that autism had some biological, as well as psychological, basis.

On the other hand, Bettelheim adhered to a psychodynamic explanation of autism which blamed the "refrigerator" mother--mothers who lacked warmth and motherly instincts--for causing normal infants to withdraw into autism.

Recent studies comparing parents of autistic children to parents of normal children have not shown significant differences or deficits in infant and child rearing skills. Thus, Bettelheim's "refrigerator mother" and psychoanalytical treatment model for autism have been largely discounted. Today there is mounting evidence that autism is a distinct physical condition whose origins probably lie in biological, rather than emotional, abnormalities. Thus, autism is now considered to be a physical condition resulting in abnormal behavior and mental development.

SECTION THREE: SPECIALISTS WHO PROVIDE DIAGNOSIS AND TREATMENT

WHERE SHOULD I TAKE MY CHILD FOR A DIAGNOSIS?

It is difficult to know where to start when you suspect that your child may have an emotional disorder. Probably the safest and easiest place to begin is with the physician your child has been seeing on a regular basis--either a pediatrician, general or family practice physician.

When you make the appointment with the physician, explain that you would like some time to talk with the doctor privately. Prepare in advance for the appointment by gathering together all of the evidence you have about your child's problems. Make a list of your concerns so that you can discuss them item by item.

Your physician can do several things to start the diagnostic process. First of all, he or she can rule out any obvious physical diseases and conditions causing behavior problems. The doctor can then refer you to a neurologist or other medical specialist if further medical tests appear to be appropriate.

WHAT DOES A NEUROLOGIST DO?

A neurologist can perform various tests to determine whether the child's behavior problems are the result of brain or nerve damage. For example, a neurologist can conduct an E.E.G. (electroencephalogram), a test which measures electric impulses in the brain. By interpreting the results of this test, the neurologist can usually determine whether there has been brain damage. Almost all children with structural brain damage have abnormal EEG's, but an EEG is not a perfect test. Some children with normal EEG's appear to show abnormalities when nothing is really wrong. The quality of an EEG depends upon the competence of the technician making the recording and the skill of the physician who interprets the results.

WHAT IF THE PROBLEM IS DEFINITELY NOT PHYSICAL?

Once physical problems have been ruled out, your physician may refer you to a psychiatrist, psychologist or mental health clinic for further diagnosis. Most doctors who see many children encounter enough emotional disorders and make enough referrals that they become familiar with at least one or two individuals who work well with children who are emotionally disturbed. However, if you live in a small community with few resources, it may be necessary for your physician to refer you to a larger community at some distance where the facilities and professional personnel are unfamiliar. In this case, both you and your physician may have to make extensive inquiries to find the right person to work with your child. If your physician is not able or willing to make an appropriate referral, contact your local mental health clinic and ask for a list of qualified therapists.

Minority families and those with non-traditional lifestyles need to be certain that professionals consider their children's unique cultures both in measurements of emotional disorders and in their treatment. Professionals need to consider the unique tendency of some cultures to present emotional disturbances in ways possibly related to social and cultural factors.

Culturally appropriate adaptations of existing intelligence and dysfunction measurements are increasingly available for minority children. Multiple procedures and tests should be used to ensure that the description selected for the child is the most accurate one. It is also necessary to assure that the child understands the tasks required for the test. It is recommended that testing should focus on describing behavior and abilities rather than on reporting one single score. The scoring of the tests, likewise, should take into account the ethnicity of the child. Tests should be used along with other information for minority children.

HOW SHOULD I CHOOSE A THERAPIST FOR MY CHILD?

There are a number of different types of therapists available in the mental health field and, unfortunately, a number of charlatans who exploit parents who are looking for help for their children. It is absolutely critical that you investigate the credentials of the therapist you choose.

1. Contact the state licensure boards for social work, psychology and/or medicine to determine whether the therapist you are considering is licensed in your state. Be very skeptical of anyone who is not properly licensed.

2. Inquire of your medical insurance company whether your insurance covers the cost of seeing the type of therapist you are considering.

3. Ask the therapist for information about his or her training and background.

4. Be sure that your therapist's training provides him or her with the expertise to diagnose and treat your child's problems.

5. Do not hesitate to seek a second opinion if you are not satisfied with the first therapist.

6. Change therapists if you or your child do not relate well to that individual.

WHAT KINDS OF THERAPISTS ARE AVAILABLE?

PSYCHIATRIST. Any licensed physician can practice psychiatry if he or she has an interest in that field. However, fully-trained psychiatrists have special training in the field, including an internship and residency in psychiatry, and then pass an examination which allows them to be board certified in psychiatry. Child psychiatry is a sub-specialty in psychiatry that requires additional training and experience.

Fully-trained psychiatrists can diagnose and treat emotional disorders. Since they are licensed physicians, psychiatrists are able to prescribe tranquilizers, sedatives, stimulants, and antidepressants which are helpful in treating some disorders. No other type of mental health professional can prescribe drugs.

PSYCHOANALYST. Any individual can call him or herself a psychoanalyst. A psychoanalyst is someone who diagnoses and treats emotional disorders through an analysis of the facts of a patient's mental life.

If psychoanalysis seems like a desirable type of therapy for your child, look for a psychoanalyst who can provide evidence of specific training in the techniques of psychoanalysis. Preference should be given to psychiatrists who have chosen to specialize in psychoanalysis. With a psychiatrist you are more assured of the individual's considerable training.

PSYCHOLOGIST. Individuals who call themselves psychologists may actually come from a variety of different backgrounds. They may or may not have a college degree. Once again, it is important to look at the individual's credentials and see what they mean.

> Clinical Psychologist. A clinical psychologist is an individual who has studied behavior and mental processes and is trained in the evaluation and treatment of emotional disorders. In most states, an individual must have a Ph.D. (a doctorate) in clinical psychology to be licensed in that field.
>
> School Psychologist. A school psychologist has studied mental processes and behavior and is prepared to deal with behavior problems in the school setting. This individual is also trained to administer intelligence, aptitude and achievement tests and relate the results of these tests to school performance. School psychologists have to be licensed in most states and generally have at least a master's degree level training.

PSYCHOTHERAPIST. Psychotherapist simply means an individual who treats emotional disturbances. It is such a general term that it is really meaningless without some additional indication of the individual's training and background.

SOCIAL WORKER. The term social worker is sometimes used very loosely. In some states, individuals with no particular training or background in social work, but who perform social work functions, are called "social workers." In the mental health field, the types of individuals who are likely to be helpful as therapists are persons with training and licenses in the fields of clinical or psychiatric social work.

Clinical Social Worker. A clinical social worker is trained in social work techniques such as individual case work or group work and holds an M.S.W. (master's) or D.S.W. (doctorate) degree.

Psychiatric Social Worker. Some social workers specialize at the master's and/or doctorate level in working with psychiatric patients and their families. An individual with this level of training and background is a psychiatric social worker.

NURSE. Registered nurses (RN) sometimes receive instruction in their nursing training in the care of patients who are emotionally disturbed or in emotional problems that accompany physical illnesses.

Psychiatric Nurse. Some nurses specialize at the master's degree level in the care of emotionally disturbed patients.

COUNSELOR. "Counselor" is another general term which really has no meaning, since individuals from a variety of backgrounds can call themselves counselors.

Family Counselor. "Family counselor" is also a nonspecific term. If a family counselor is also a licensed psychologist, psychiatrist, or social worker, then the individual may have the training and background to work with families. Be skeptical of family counselors who do not have degrees and licenses in mental health fields.

Guidance Counselor. A guidance counselor is an individual working in a school who is trained (at the bachelor or master's degree level) to do screening, evaluation and career and academic placement. This type of counselor may also do some limited personal counseling. In addition, the school guidance counselor often has primary responsibility for communications with the home, consultation during crisis situations, development of mental health programs and counseling in small group settings.

Christian Counselor. Some counselors claim to provide religiously-oriented therapy. If it is important to you that your child receive this type of therapy, first locate a therapist with the proper training and license. Then see if any of the therapists with credentials also provide a religious orientation in their therapy.

Indigenous Counselor. Choice of therapist is also dictated by culture; for example, some cultures make significant use of folk healers. The traditional healing practices of minorities are being incorporated gradually into contemporary mental health treatment approaches. Minority families should assure that treatment is available for their children that combines respect for and an understanding of their culture, is presented in language their child understands, and is appropriate for their culture. A combination of the use of an indigenous counselor and another, more-mainstream, therapist might be most beneficial to their family, if the two communicated effectively.

SHOULD I CONSIDER COST WHEN CHOOSING A THERAPIST?

Cost is, of course, something to think about when choosing a therapist. There is a wide range of fees which various types of therapists charge; however, in general, psychiatrists are the most expensive therapists, followed by psychologists and social workers. Individual therapy is more expensive than group therapy. Mental health clinics often have sliding fee scales based upon family income. School services for qualifying children are free.

Here are some things to consider about the cost of therapy:

1. Choose the type of therapist who can meet your child's needs. Psychiatrists are, in general, more expensive than other types of therapists, but they can provide some services which others cannot provide. If your child needs a psychiatrist, then cost has to be a secondary consideration.

2. If at all possible, choose a therapist whose fees are covered by your health insurance. Sometimes insurance companies will only pay if the referral to a therapist is made by a medical doctor. Be sure that you have such a referral. Many medical insurance companies have limited plans for psychological care. Be sure to read the fine print on your policy before you go too far.

3. Choose the least expensive option which still gets the job done. Sometimes a child can be helped by having a few initial visits with a psychiatrist or psychologist, then follow-up visits with a social worker or school counselor. This combination of therapists would be much less expensive than seeing a psychiatrist several times.

SECTION FOUR: SERVICES AVAILABLE FOR CHILDREN

WHAT TYPES OF SERVICES ARE AVAILABLE FOR CHILDREN WITH EMOTIONAL HANDICAPS?

There is probably nowhere in the United States where a full range of services for children with emotional disturbances exists. But parents of these children need to know what the possibilities are. Here is a set of ideal options ranging from the least restrictive (most natural setting) to the most restrictive setting:

HOME INTERVENTION. The purpose of the home-based model of treatment is to provide intensive in-home crisis intervention to prevent placing children outside their homes away from their families. Such programs are directed toward managing crises and teaching families new ways of resolving problems to prevent future crises.

Successful home intervention programs have therapists available to families 24 hours a day for four to six weeks. During this period, families receive regular training sessions in their homes and may call on the therapists for help any time a crisis arises.

The therapists are trained in behavior interventions, client-centered therapy, values clarification, problem solving, crisis intervention and assertiveness training. They also provide assistance with home management and budgeting skills, advocacy, and referral for legal, medical or social services.

Intensive home-based treatment facilitates an accurate assessment of the child and of the family's functioning. Home-based treatment also enables the therapist to model and shape new behaviors in the child's normal environment. Therapists can directly observe the treatment plan and revise it as necessary.

SCHOOL-BASED SERVICES. Schools must provide appropriate special education for children who are identified as seriously emotionally disturbed and in need of special educational help. For qualifying children, school staff and parents write an Individualized Education Program (IEP) which specifies the amount and type of special education the child requires, the related services the child may need, and the type of placement which is suitable for providing the child's instruction. Related services may include psychotherapy if services are necessary for the child to benefit from his or her education.

It is important to note that special education services are specifically educational in nature. While these educational services may be helpful to the emotionally disturbed child, they may not constitute a complete treatment program.

Special education services must be provided at no cost to parents. The Individualized Education Program must be revised annually, with parents participating in the revision.

COMMUNITY-BASED OUTPATIENT TREATMENT. Outpatient treatment usually means that the child lives at home and receives psychotherapy at a local mental health clinic or from private therapists. Sometimes psychotherapy is combined with a home intervention and/or a school-based special education program. Outpatient therapy may involve individual or group therapy or a combination of the two.

COMMUNITY-BASED DAY TREATMENT. Day treatment is the most intensive non-residential type of treatment. It has the advantage of keeping the child in the home, while bringing together a broad range of services designed to strengthen the child and improve family functioning. The specific features of day treatment programs vary from one program to another, but may include some or all of the following components:

- special education, generally in small classes with a strong emphasis on individualized instruction;
- psychotherapy, which may include both individual and group sessions;
- family services, which may include family psycho-therapy, parent training, brief individual therapy with parents, assistance with specific tangible needs such as transportation, housing or medical attention;
- vocational training, particularly for adolescents;
- crisis intervention;
- skill-building with an emphasis on interpersonal and problem-solving skills and practical skills of everyday living;
- behavior modification;
- recreation therapy, art therapy, and music therapy to aid social and emotional development; and
- drug and/or alcohol counseling.

Children typically participate in a day treatment program for at least five hours a day, and lengths of stay are generally at least one school year and often more.

Many day treatment programs, are physically located on a school site. In these cases, they often have a wing of their own that includes classrooms and office space. Other programs are run in mental health centers, other community agencies, or on the grounds of a hospital or private clinic.

COMMUNITY-BASED RESIDENTIAL PROGRAMS. Community-based residential programs involve the use of either group homes or therapeutic foster homes. This type of treatment assumes that there is a need to bring about a total change in the child's environment.

> Foster-Home Placement. A foster home is in many ways a "natural" approach to providing treatment because it provides a family unit which is the customary developmental situation for a child. A therapeutic foster home is supposed to provide additional components beyond the nurturing characteristics of a well organized family. These additional components may include special training for the foster parents in behavior modification and crisis intervention, as well as access to psychotherapy, social work service, and other community resources.

Group Home Placement. Placement in a group home is somewhat more restrictive than foster care, since the living situation is not totally "natural." Group homes provide family-style treatment in a more structured setting than the natural environment. Treatment usually involves a combination of evaluation, psycho-therapy, use of behavior modification, peer interaction, and increasing self-government.

RESIDENTIAL TREATMENT CENTERS. Residential treatment centers provide round-the-clock treatment and care for children with emotional disturbances who require continuous medication and/or supervision or relief from stresses in the environment, or whose families require relief from the stress of caring for them.

A number of residential treatment centers for severely emotionally disturbed children have developed throughout the United States. Many of these facilities focus on a particular treatment philosophy (e.g., Bruno Bettelheim's Orthogenic School). Generally, residential centers base their treatment on the premise that the child's total environment must be structured in a therapeutic way. Some emphasize particular diets and exercise regimes; others concentrate on behavior modification programs which function in the classrooms and in the dormitories as well; still others use a patient-centered, "structured-permissiveness" approach. Some treatment centers are set up to deal specifically with alcohol and drug related problems.

While residential treatment centers have academic programs, a great deal of attention is directed to the child's emotional problems, regardless of whether they are associated with academic matters. Considerable time and effort is spent on group and individual therapy and therapeutic social activities.

RESIDENTIAL CARE/HOSPITAL OR TRAINING SCHOOL. Residential care in a hospital or training school tends to be the most restrictive type of treatment which comes about after other, less intrusive forms of treatment have been tried and have failed, or when a child has violated the law and been ordered by the court to a particular facility.

Psychiatric Hospital. A psychiatric hospital is a medical facility whose emphasis is on medical solutions to mental problems. Psychiatric hospitals tend to use medications and sometimes other physiological interventions. Hospitals which serve children must provide educational opportunities for them, but the primary mission of these facilities is not academics.

Training School. Training schools are generally a type of correction facility which is intended to serve delinquent youth. Depending on the level of financial support and degree of commitment from state government, some training schools offer psychotherapy, behavior modification programs and/or vocational training. In general, training schools are not desirable treatment facilities because they are usually underfunded and restricted to prison-like programs. All training schools are required by federal law to provide appropriate special education for children who qualify.

ARE SUPPORT SERVICES AVAILABLE FOR PARENTS?

Parents of emotionally disturbed children are forming self-help support groups across the country. A parent from Parents Involved Network (PIN in Philadelphia) describes the functions of a support group this way:

> *Parents in self-help groups run by parents decide for themselves what they need to do. They organize or join a group with other parents, depend on one another for emotional support and practical guidance and, in most cases, unite with each other to challenge institutional and political decisions that harm or threaten their children...*
>
> *Self-helping parents are in a unique position to emphathize with the parents who call on them and are accessible in a way that professionals seldom are. Their concerns go beyond their own children and beyond the children of other parents who call on them for help. These parents almost always become interested in changing the institutions that provide services for their children and reforming the laws that govern these services.*
>
> *An important point is the passion that parents bring to advocacy for large-scale change springs from their own acute, painful experiences. Resourceful parents can make our policies, institutions, agencies and governments vibrant with respect for the power--and that's a big word--the power of parents. By depending on ourselves, making demands on the system, fighting for our children, parents and professionals can work together to try to get services that meet the needs of our children and to make professionals responsive to parents as well.*

For information about a parent group in your area, contact these organizations:

Research and Training Center*
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(503) 464-4040

Federation for Children with Special Needs
312 Stuart Street, 2nd Floor
Boston, Massachusetts 02116
(617) 482-2915

---

*The Families as Allies Project, Research and Training Center, Portland State University, publishes the *National Directory of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth.*

RESPITE SERVICES

Respite services involve the provision of short-term temporary care with the primary purpose of offering relief to the caregiver or caregivers of a person with disabilities. Respite care, then, is a service to the family, not only to the child who is the usual focus for services. Although there are currently few respite programs designed specifically for families of children with emotional handicaps, the importance of respite care is being increasingly recognized by parents and service providers alike. For a number of years there have been respite services for families of the elderly and families of children with physical or developmental disabilities. Much of the information in this section is drawn from existing programs for those populations, but can be applied to the provision of respite care services to families of children with emotional or behavioral difficulties.

The immediate goal of respite care is to give parents or other caregivers a "break" from the continuous tasks and pressures of caring for a child with special needs, but there are equally important long-range goals. By having periods of relief, or knowing that they are available when needed, a family's level of stress can be significantly reduced. Therefore, the family's ability to care effectively for the child and cope with ongoing family issues is increased. Using respite services does not indicate that parents are unable to care for their child. Caring for a child with special needs is a very intense, high-pressure activity. Regularly scheduled and anticipated breaks can only enhance a parent's effectiveness.

Respite programs can take many forms. Care may be provided in the family's home, allowing caregivers the chance to get away, or may take place in the respite provider's home. In some cases, residential centers set aside a few beds for respite; in others, facilities such as community centers may be used for regular weekend or after-school programs. Depending on program structure, respite care is typically provided for a few hours, a day or a weekend. Longer periods of care are offered by some programs, usually related to the severity of a client's disability or a special family situation.

Respite providers may be volunteers or may be paid, but in either case they should be trained in working with children who have emotional handicaps as well as in first aid skills. Costs to parents vary from program to program. Services may be free, paid on a sliding fee scale, or at a set rate. In some cases, respite workers are paid directly by parents, with a central agency recruiting, training and matching the workers with families. Variations on this approach include subsidies to low-income families to help pay providers, and programs which allow parents to choose their own provider (perhaps a friend or relative) who is then paid by the agency.

Parent-run programs, sometimes called parent cooperatives or co-ops, have provided an innovative response to the need for respite services. Initiated by parents of children with various handicaps, some of these have expanded to include parent support groups, formal training, or even have become established agencies. There are several advantages to this approach. For example, parents can feel confident that their child is being cared for by someone who understands the nature of his or her needs and behaviors; there is a greater chance that the family and providers know each other, reducing concerns over a child being left with "strangers"; and parents are in control of funding and administrative mechanisms, assuring that the program truly meets the needs of families.

Even when parents do not directly control respite programs, their input remains crucial. Serving on advisory boards, participating in program and service evaluations, and interviewing potential providers are some of the ways that parents can influence the quality of respite services they will receive.

Although some communities do have respite services for families of children with emotional handicaps, most do not. Existing programs might be located through Information and Referral (I&R) systems (such as those provided by United Way) or child welfare agencies. If no programs are available, or existing programs do not appropriately address the child's needs, parents can take steps to have respite services developed. For example, programs serving children with physical or developmental disabilities may be interested in expanding to serve children with emotional problems. Parent demand and input into training and program structure are often required in order for them to do so. Other potential settings that may also be sources for qualified staff are local residential and day treatment programs serving children with emotional handicaps. Community resources such as camps, schools, and summer or weekend activity programs can be encouraged to include staff trained to work with children who may have behavioral difficulties. Local vo-tech (vocational and technical) schools and community colleges often have child care or health care curricula that can be expanded to include training in working with special needs children. New respite care programs can be initiated by forming parent cooperatives, or by working through agencies that provide other complementary services. Whether their goals are to expand existing programs or to implement new ones, parents will increase their effectiveness by involving funding sources, advocacy groups, agency administrators, and legislators.

When a program is located, parents will need to find out about cost, where care is provided (in-home, out-of-home), and what their responsibilities are regarding transportation and availability in case of emergency. Seeking information on training and supervision of providers is important to assure that quality care will be given to the child. Respite providers should be flexible in meeting the family's needs and willing to be a part of the child's overall system of care by communicating with parents, teachers and other persons involved with the child.

The lack of respite services for families of children with emotional handicaps highlights this as an important area for advocacy by parents. Parent demand was a key factor in the establishment of respite programs for caregivers of children with physical and developmental disabilities. It will also play a significant part in respite care becoming a regularly accessible support service to families of children with emotional handicaps.

EXERCISES

QUESTIONS

The following exercises provide an opportunity for you to think about what you have read in this chapter. The page numbers for each exercise indicate the section of the text on which the questions are based. Answers for the exercises are on page 43.

EXERCISE Section 1 Number 1 (pp. 24-25)

Without referring to the text, fill in the blanks in the sentences below.

1. In the biological model, it is assumed that emotional disturbance is caused by

____

____

2. The biological model relies on two basic types of treatment

a.____

b.____

3. In psychoanalysis, the causes of emotional disturbance are assumed to be

____

____

4. Behavioral therapists try to change behavior by providing

a.____

b.____

5. In the ecological model, treatment involves

____

____

EXERCISE Section 1 Number 2 (pp. 24-25)

Define the following terms in your own words.

1. Psychotherapy means________________________________

2. Play therapy means________________________________

EXERCISE Section 2 Number 1 (pp. 26-31)

Match the following terms with their definitions.

1. Conduct Disorder ______
2. School Phobia ______
3. Schizophrenia ______
4. Pervasive Developmental Disorder ______
5. Post-traumatic Stress Disorder ______
6. Oppositional Disorder ______
7. Adjustment Disorder ______
8. Attention-deficit Hyperactivity Disorder ______
9. Anxiety Disorder ______
10. Hyperactivity ______

A. A condition characterized by a failure to remain attentive in situations where it is socially necessary to do so.

B. A condition characterized by severely disorganized behavior and personality.

C. Repetitive, persistent pattern of conduct that violates the rights of others.

D. Aggressive behavior displayed by obstinateness and passivity.

E. Separation anxiety brought about by leaving home for school.

F. Excessive movement or activity.

G. Anxiety disorder following a traumatic event.

H. Extreme distortions or delays in the development of social behavior and language.

I. Maladaptive reaction to an unidentifiable source of stress.

J. Abnormal fears of perceived internal or external dangers.

EXERCISE Section 3 Number 1 (pp. 32-36)

List the kinds of things each of these professionals contribute to a diagnosis of an emotional disorder.

1. Pediatricians
2. Neurologists
3. Clinical Psychologists
4. Psychiatrists
5. School Psychologists

EXERCISE Section 3 Number 2 (pp. 32-36)

On the following pages is a series of advertisements from the telephone book. List the therapists that appear to have appropriate credentials for working with emotionally disturbed children and adolescents.

1. **UPTOWN PSYCHOLOGICAL CLINIC**
DR. MICHAEL TILLSON
Licensed Clinical Psychologist
Marriage & Family Counseling
Divorce Mediation
Psychological Evaluations and
Expert Legal Testimony
555-8916

2. **PSYCHOLOGICAL SERVICES**
CARING CHRISTIAN PROFESSIONALS
Silas Warne, Ph.D.
Frank Miles, Psy.D.
LICENSED CLINICAL PSYCHOLOGISTS
Sara A. Fine, Ph.D.
Malcolm Sves, M.A.
Clinical Associates
INDIVIDUAL, MARITAL, FAMILY,
GROUP PSYCHOTHERAPY
LEGAL, PASTORAL CONSULTATION
No fee for initial consultation.
555-2154

3. **NORTH CASCADES PSYCHOLOGICAL CLINIC**
LICENSED CLINICAL PSYCHOLOGISTS
F. J. Frankel, Ph.D.
Cyril Wallace, Ph.D.
Nancy Knight, Ph.D.
CHILDREN, ADULTS, ADOLESCENTS, COUPLES
PSYCHOTHERAPY
MARRIAGE & FAMILY
COUNSELING
EATING DISORDERS
NEUROPSYCHOLOGICAL EVALUATIONS
555-0010

4. Sampson & Smith
Individual, Marital, Adult, Child
Family Counseling
R. Sampton, M.A., M.C.
N. Smith, R.N., M.S.
555-6303

5. Karen Burns
Practice of Psychotherapy
Individuals and Groups
Marital-Sexual Therapy
Insurance Accepted
Licensed Clinical Social Worker
M.S.W., A.C.S.W.
555-6303

6. TED SEELEY
The Troubled Family
Individual, Marital & Family Therapy
Diagnosis & Treatment
STRESS
555-1001

7. Uptown Psychological Services
Carter James, Ph.D.
Melvin Clement, Ph.D.
Licensed Clinical Psychologists
Individual & Family Psychotherapy
Sex Therapy
555-6526

8. Nick Able
Ed.D. Licensed Psychologist
Individual, Family, &
Marital Therapy
Psychological Evaluations
555-6502

9. Clinical Psychology Services
DR. NORA THOMAS
RIVERSIDE FOUR
555-1240

10. Mary North
CHILDREN & ADULTS
INDIVIDUAL AND FAMILY THERAPY
PSYCHOLOGICAL EVALUATIONS
Associated with the Eastside Clinic
555-5925

11. Fred Sims, Ph.D.
CLINICAL PSYCHOLOGIST
Individual, Marital, & Family Therapy
Children, Adolescents, Adults
Psychological Evaluations
Divorce Adjustment Therapy
555-0876

12. PSYCHOLOGICAL ASSOCIATES
CLINICAL PSYCHOLOGIST
CHILDREN+ADOLESCENTS+ADULTS
PSYCHOLOGICAL EVALUATIONS
& PSYCHOTHERAPY
Gary Brown, Ph.D.
555-1224

13. NEW STRESS CENTER **HYPNOTHERAPY**
weight control, bulimia
smoking, agoraphobia, chronic
pain, migraine
STRESS
555-7725

EXERCISE Section 3 Number 3 (p. 32-36)

After examining these advertisements for credentials, what are two additional steps you could take to investigate these therapists?

1. ____

2. ____

EXERCISE Section 4 Number 1 (pp. 37-42)

Arrange these types of services in order from the least restrictive (most normal) to the most restrictive.

1. Day Treatment
2. Outpatient Treatment
3. Training School
4. Residential Treatment Center
5. Home-Intervention
6. School-Based Services

EXERCISE Section 4 Number 2 (pp. 37-42)

TRUE or FALSE

T F 1. Home intervention services are usually long-term services,extending over one or more years.

T F 2. Schools must provide psychotherapy as a related service for special education students who require it to benefit from their education.

T F 3. Schools charge parents on a sliding scale basis for special education.

T F 4. Day treatment is the most intensive non-residential type of treatment.

T F 5. Therapeutic foster homes provide a more natural treatment option than group homes.

T F 6. Residential treatment centers base their treatment on the premise that the child's total environment must be structured in a therapeutic way.

T F 7. Psychiatric hospitals provide medical and therapeutic treatment, but they do not have to provide children with educational opportunities.

T F 8. Many day treatment programs are physically located in schools.

T F 9. Group homes provide family-style treatment in a more structured setting than the normal family environment.

T F 10. Incarcerated children lose their right to special education.

ANSWERS

HOW DID YOU DO? EXERCISE 1.1 (p. 43)

1. physical problems such as genetic defects, poor nutrition, birth or accidental injury, physical illness, poisoning, or poor sleep habits.

2. (a) drugs and (b) changing environmental conditions.

3. the result of psychological conflicts in the patient's past.

4. positive reinforcement for desirable behavior and ignoring (known as extinction) or negative reinforcement for undesirable behavior.

5. intervention with both the individual and his or her environment.

HOW DID YOU DO? EXERCISE 1.2 (p. 44)

1. Psychotherapy means the treatment of mental and emotional disorders.

2. Play therapy means a type of psychoanalytic therapy designed for children which involves using structured play situations to help a child gain insight into his or her behavior.

HOW DID YOU DO? EXERCISE 2.1 (p. 45)

1. C
2. E
3. B
4. H
5. G
6. D
7. I
8. A
9. J
10. F

HOW DID YOU DO? EXERCISE 3.1 (p. 46)

Answers will vary.

1. Knows patient's history
   Knows family
   Can rule out physical problems
   Can refer parents to other medical professionals

2. Can identify brain and/or nerve damage
Can give and evaluate an EEG

3. Can evaluate and treat emotional disorders

4. Can perform both mental and physical diagnostic tests
Can prescribe drugs and evaluate their effects

5. Can administer intelligence, aptitude, and achievement tests
Can prescribe drugs and evaluate their effects

HOW DID YOU DO? EXERCISE 3.2 (pp. 46-49)

1. Dr. Michael Tillson, Clinical Psychologist

2. Silas Warne, Ph.D., Clinical Psychologist
Frank Miles, Psy.D., Clinical Psychologist

3. F. J. Frankel, Ph.D., Clinical Psychologist
Cyril Wallace, Ph.D., Clinical Psychologist
Nancy Knight, Ph.D., Clinical Psychologist

4. N. Smith, RN, Registered Nurse

5. Karen Burns, MSW, Clinical Social Worker

6. Unable to determine qualifications from listing.

7. Carter James, Ph.D., Clinical Psychologist
Melvin Clement, Ph.D., Clinical Psychologist

8. Nick Able, Ed.D.; Psychologist

9. Unable to determine qualifications from listing.

10. Unable to determine qualifications from listing.

11. Fred Sims, Ph.D., Clinical Psychologist

12. Gary Brown, Ph.D.; Clinical Psychologist

13. Unable to determine qualifications from listing.

HOW DID YOU DO? EXERCISE 3.3 (p. 49)

1. Inquire with state licensure boards to see if these individuals hold current licenses in their fields (psychology, social work, counseling, psychiatric nursing).

2. Inquire about the types of training, schools attended, and professional association memberships of these individuals.

HOW DID YOU DO? EXERCISE 4.1 (p. 50)

1. Home Intervention
2. School-Based Services
3. Outpatient Treatment
4. Day Treatment
5. Residential Treatment Center
6. Training School

HOW DID YOU DO? EXERCISE 4.2 (pp. 50-51)

1. F
2. T
3. F
4. T
5. T
6. T
7. F
8. T
9. T
10. F

REFERENCES/BIBLIOGRAPHY

Several of the publications listed below have been important in shaping the thinking of mental health professionals. These materials are not "light" reading for lay persons, but they provide helpful insights into the background and terminology common to professionals.

The more recent publications listed reflect current research and outline contemporary trends in the mental health field.

These publications were not written for "parent" consumption, so parents may find some of their contents objectionable or even offensive. Some of the books contain theories which recent research has refuted. The value of these publications is not so much for their applicability today, but for the perspective they give parents on where the mental health field has been and where it may be headed.

Because of their specialized nature, some of these publications are not available in local book stores and libraries, so it may be necessary to use an interlibrary loan system or to consult a college, university or medical library.

Adams, P.L. (1974). *A primer of child psychotherapy.* Boston: Little, Brown.

American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders.* (3rd Ed. Revised). Washington, D.C.: American Psychiatric Association.

Anderson, C. M., Reiss, D.J., & Hogarty, G.E. (1986). *Schizophrenia in the family: A practitioner's guide to psycho-education and management.* New York: Guilford Press.

Andreasen, N.C. (1984). *The broken brain: The biological revolution in psychiatry.* New York: Harper & Row.

Axline, V. (1947). *Play therapy.* Boston: Houghton Mifflin.

Bandura, A. (1969). *Principles of behavior modification.* New York: Holt, Rinehart & Winston.

Bettelheim, B. (1950). *Love is not enough.* Glencoe, IL: Free Press.

Bettelheim, B. (1967). *The empty fortress.* Glencoe, IL: Free Press.

Dreikurs, R. & Grey, L. (1970). *A parent's guide to child discipline.* New York: Hawthorne Books.

Erikson, E.H. (1950). *Childhood and society.* New York: W.W. Norton

Erikson, E.H. (1968). *Identity, youth and crisis.* New York: W.W. Norton.

Falloon, I., Boyd, J.L. & McGill, C.W. (1984). *Family care of schizophrenia.* New York: Guilford Press.

Freud, A. (1965). *Normality and pathology in childhood.* New York: International Universities Press.

Freud, S. (1963). Introductory lectures on psychoanalysis. In J. Strachey (Ed. and Trans.), *The standard edition of the complete psychological works of Sigmund Freud.* (Vol. 16, p. 393). London: Hogarth Press.

Glasser, W. (1965). *Reality therapy.* New York: Harper & Row.

Goldfarb, L.A., Brotherson, M.J., Summers, J.A., & Turnbull, A.P. (1986). *Meeting the challenge of disability or chronic illness--A family guide.* New York: Paul H. Brookes.

Greenfield, J. (1973). *A child called Noah.* New York: Paperback Library.

Herzov, L., Berger, M. & Shaffer, D. (Eds.). (1978). *Aggression and antisocial behavior in childhood and adolescence.* London: Pergamon Press.

Kanner, L. (1973). *Childhood psychosis: Initial studies and new insight.* Washington, D.C.: Winston & Sons.

Kaplan, H.I. & Sadogh, B.J. (Eds.). (1985). *Comprehensive textbook of psychiatry.* II. (4th ed.). New York: Williams & Wilkins.

Lewis, D.O. (Ed.). (1981). *Vulnerabilities to delinquency.* New York: Spectrum.

Jung, C. (1959). *Basic writings.* New York: Modern Library.

Lovaas, I. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied Behavior Analysis*, 6, 131-166.

Maslow, A. (1962). *Toward a psychology of being.* Princeton, NJ: D. Van Nostrand Co.

McDermott, J.F. & Harrison, S.I. (Eds.). (1977). *Psychiatric treatment of the child.* New York: Jason Aronson.

Miller, D. (1983). *The age between: Adolescence and therapy.* New York: Jason Aronson.

Mosak, H. & Dreikurs, R. (1973). Adlerian psychotherapy. In R. Corisinni (Ed.), *Current psychotherapies.* Itasca, IL: F.E. Peacock, Inc.

Prugh, D.G. (1983). *The psychological aspects of pediatrics.* Philadelphia, PA: Lea & Febiger.

Redl, F. (1966). *When we deal with children.* New York: Free Press.

Reid, W.H. (1983). *Treatment of the DSM-III psychiatric disorders.* New York: Bruner Mazel.

Rhodes, W.C. (1967). *The disturbing child: A problem in ecological management.* Exceptional Children. 33. 449-455.

Rimland, B. (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior.* New York: Appleton-Century-Crofts.

Rimland, B. (1969). Psychogenesis versus biogenesis: The issues and evidence. In S.C. Plog & R.B. Edgergon (Eds.), *Changing perspectives in mental illness.* New York: Holt, Rinehart & Winston, Inc.

Rogers, C. (1951). *Client-centered therapy.* Boston: Houghton Mifflin Co.

Ross, A. (1974). Psychological disorders of children: A behavioral approach to theory, research, and therapy. New York: McGraw-Hill.

Rutter, M. & Schopler, E. (Eds.). (1978). *Autism: A reappraisal of concepts and treatment.* New York: Plenum Press.

Shaw, C.R. and Lucas, A. (1970). *The psychiatric disorders of childhood.* (2nd ed.). New York: Appleton-Century-Crofts.

Westermeyer, J. (1987). Clinical considerations in cross-cultural diagnosis. *Hospital and Community Psychiatry*, 38(2), pp. 160-173.

Williams, C.L. (1987). Issues surrounding psychological testing of minority patients. *Hospital and Community Psychiatry*, 38(2), pp. 160-173.

Wing, J. (1974). *Early childhood autism.* (2nd ed.). London: Pergamon Press.

CHAPTER THREE: UNDERSTANDING THE LAW

As you seek help for your emotionally disturbed child, you gather information from a variety of sources. Much of that information comes from predictable fields like medicine and education, but you may be surprised to learn that it is also necessary for you to become familiar with the law as well.

To protect your rights as a parent and to secure an appropriate education for your child, you will need to know about Public Law 94-142, the Education of All Handicapped Children Act. In addition, you may need to be familiar with the juvenile justice system since there are sometimes conflicts in that system between parents' rights and the rights of the state.

As you become more familiar with the law, you will begin to see that it presents mixed blessings. The law can be a source of comfort and assistance to parents whose children have emotional disturbances because it guarantees that your child cannot be discriminated against on the basis of his or her handicap. Further, your child must have access to the opportunities which are available to other children in the community. If the schools or other government agencies appear to be violating your child's rights, you have recourse through the law.

On the other hand, you may sometimes find your wishes as a parent conflict with certain regulations, particularly in the juvenile justice system. For example, in some states it is necessary for parents to relinquish custody of their child so that the child can receive residential treatment at state expense.

Knowing your rights and understanding the legal system can be a tremendous help as you advocate for your child. This chapter provides some basic information about the law. But please regard the answers to the questions in this chapter as just a beginning. Because these materials are written for a widely divergent audience across the United States, it is not possible to give detailed information about specific laws in particular states. It is very important for you to go further and investigate the laws in your own state. In addition, the law is a dynamic force. As courts decide cases and as new legislation is enacted, the law continues to evolve. Do not assume that this chapter presents the last word on legal matters. For the most current and most specific information, consult a lawyer or an advocacy group in your state.

It may be a little difficult at first sorting through all the legal language, but as your understanding grows, you will find strength in some aspects of the law. It is reassuring to know that federal and state laws protect the rights of emotionally disturbed children.

Finding out about those aspects of the law which are unclear or unfair to emotionally disturbed persons will give you an agenda for reform in your community and state. Knowing the law can help you to obtain appropriate services for your child and assure that his or her dignity and personal worth are respected.

In this chapter, each case described includes a "citation" which indicates where it may be found. A librarian can assist you in locating the case.

SECTION ONE: LABELS

WHAT DO LABELS MEAN?

One of the most frustrating things about having children with emotional problems is that they often receive a variety of labels, depending upon which agency you consult. There is no question that the mental health field is complicated and that professionals within the field have widely divergent opinions about what the "correct" labels ought to be. Because of this widespread disagreement, it is difficult to make generalizations about the field and the labels that are used. The following is an attempt, however, to give you some insight into what is going on behind the scenes.

Labels are often the result of the basic attitude that a professional has toward emotional problems. Some professionals are most interested in the causes of emotional disturbances, so the labels they use reflect that interest. Other professionals have no interest in causes, but are strictly concerned with outward behavior and how that can be changed. Still other professionals focus on possible physical origins for emotional problems. So one child, seen by a variety of professionals, may acquire a series of labels reflecting the viewpoints of all the professionals involved. The trick for the parent is to try to make sure that the labels a child bears are (1) truly descriptive in some way of the problem and (2) lead to helpful treatment and/or education solutions.

There is nothing magic or particularly important about a label unless it leads to appropriate action for the child. Mislabeling a child, on the other hand, can be extremely detrimental because an incorrect label can lead to inappropriate treatment. To prevent mislabeling, you must be diligent in asking what the label means. If you are not satisfied that a label describes your child accurately, state your concern and seek other professional opinions.

WHAT ARE SOME COMMON LABELS AND WHAT DO THEY MEAN?

AUTISM. A disorder (usually appearing by age 2) characterized by lack of communication, lack of social skills, withdrawal, developmental delays, and stereotyped behavior. In general, professionals in schools view autism as a set of behaviors requiring modification and retraining. Since a high percentage of autistic individuals are also mentally retarded, autistic students often receive many of the same services in schools as mentally retarded students. Some professionals with a psychoanalytic background seek psychological causes of autism, but this approach has been largely discounted by research.

BEHAVIOR DISORDERED. Displaying over a long period of time behaviors which significantly deviate from socially acceptable norms for the individual's age and situation. Professionals using this term tend to be those more interested in changing an individual's behavior than in finding causes for the inappropriate behavior.

BRAIN-INJURED. A condition in which an individual before, during, or after birth has received an injury to or suffered an infection of the brain. As a result of such organic impairment, there may be disturbances that prevent or impede the normal learning process. This term is one that is used in the biological model.

DELINQUENT. A description applied to a child who has been found by a court of law to have violated a law. A delinquent child may or may not also be seriously emotionally disturbed.

DEVIANT. An individual who breaks rules, often of a sexual nature.

SERIOUSLY EMOTIONALLY DISTURBED. Suffering from severe disturbances of the emotional processes. This label is frequently used by those professionals who are interested in finding the causes for an individual's emotional problems. "Emotionally disturbed" is also the label used in P.L. 94-142, the federal law requiring education for handicapped children.

MENTALLY ILL. A general term applied to individuals suffering from emotional problems. "Mental illness" is assumed to be the opposite of "mental health." Professionals who are interested in causes and cures for emotional problems use the term "mentally ill."

NEUROLOGICALLY IMPAIRED. Having suffered damage to or some deficiency in the nervous system of the body; a biologically related term.

SOCIOPATHIC. Displaying extreme hostility toward and disregard of society and for all organized segments of society.

SOCIALLY MALADJUSTED. Having difficulty dealing with society and groups of people.

SECTION TWO: FEDERAL STATUTORY AND CASE LAW

WHAT FEDERAL LAWS HAVE DIRECT BEARING ON THE RIGHTS OF CHILDREN WITH EMOTIONAL DISTURBANCES?

The three most important pieces of legislation guaranteeing particular rights to children who are seriously emotionally disturbed are the Family Educational Rights and Privacy Act of 1974 (FERPA), Section 504 of the Rehabilitation Act of 1973 and Public Law 94-142, The Education for All Handicapped Children Act (EHA).

WHAT IS FERPA?

This law, sometimes called the Buckley Amendment, guarantees the privacy of school records and insures the parent's right to see, review and--if necessary--amend, a child's school records. FERPA applies to all children in school, not only to children with handicaps.

WHAT IS SECTION 504?

Section 504 is a part of the Rehabilitation Act of 1973. That section provides that no program or activity receiving federal funds can exclude, deny benefits to, or discriminate against any person on the basis of handicap. Since most schools receive federal funds, they are bound by the provisions of Section 504. Regulations attached to Section 504 apply to all states. Complaints charging discrimination can be lodged with the Office of Civil Rights.

WHAT IS PUBLIC LAW 94-142?

Public Law 94-142, The Education for All Handicapped Children Act, is a federal law which guarantees a free, appropriate public education for all handicapped children. Under this law, schools are required to seek to identify all handicapped children in their area. Further, once children are identified as handicapped, they must receive an appropriate education at no expense to their parents, regardless of the nature or severity of the handicapping condition. The legislation is often cited as P.L. 94-142.

TO WHAT AGES DOES P.L. 94-142 APPLY?

The original Education for All Handicapped Children Act passed in 1975 applied to children of school age. In October 1986, the legislation was amended (P.L. 99-457) and the mandate for special education services was extended down to age 3 with the option of further extension to birth. After school year 1990-91, a state which serves any preschool handicapped children ages 3-5 will have to serve all qualifying children or relinquish its rights to federal funds for preschool handicapped children.

Educational services cease at different ages depending upon the individual state's legislation. Some states serve children until they reach the age of 18, while others extend services to age 20, 21 or 22.

WHAT IS AN APPROPRIATE EDUCATION?

P.L. 94-142 defines appropriate education as an individual education program specially designed to meet the unique needs of the handicapped child. In addition, the handicapped child must have access to a full range of services, called "related services" which may be necessary to help the child benefit from his or her education. The law specifies thirteen possibilities for related services:

1. Audiology
2. Counseling services
3. Early assessment and identification
4. Medical services (for diagnosis of a handicap)
5. Occupational therapy
6. Parent counseling and training
7. Physical therapy
8. Psychological services
9. Recreation
10. School health services
11. Social work services in schools
12. Speech pathology
13. Transportation.

Any of these services, or others not mentioned, must be provided if they are necessary for the child to benefit from his or her education.

DO EMOTIONALLY DISTURBED CHILDREN QUALIFY FOR SERVICES UNDER P.L. 94-142?

"Seriously emotionally disturbed" (SED) is one of the handicapping conditions recognized under P.L. 94-142. The federal definition of "seriously emotionally disturbed" is:

> *...A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:*
> *(A) An inability to learn which cannot be explained by intellectual, sensory, or health factors;*
> *(B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers;*
> *(C) Inappropriate types of behavior or feelings under normal circumstances;*
> *(D) A general pervasive mood of unhappiness or depression;*

> *(E) A tendency to develop physical symptoms or fears associated with personal or school problems.*

Under the federal definition, the term includes children who are schizophrenic or autistic, but does not include children who are socially maladjusted, unless it is determined that they are also seriously emotionally disturbed.

Individual states have further refined the definition of "seriously emotionally disturbed" and may use other terminology to identify the same category. It is important to check with your state educational agency or your local school district to see how "emotionally disturbed" is defined in your state.

WHY ARE "SOCIALLY MALADJUSTED" STUDENTS EXCLUDED FROM P.L. 94-142?

The definition of "seriously emotionally disturbed" is loaded with subjective, value-laden words which do not have precise meanings. Making distinctions between a child who is "socially maladjusted" and one who is "seriously emotionally disturbed" is very difficult. The general intent of the definition of SED is to point out that there is a difference in degree between the individual who displays contrary behavior, who is a nonconformist, or who chooses to behave differently, and an individual who suffers to a "marked degree" from an inability to relate to others, extreme depression, withdrawal and social isolation, or disoriented or psychotic behavior.

Detecting these differences in degree is a subjective matter. In *Lora v. Board of Education of the City of New York*, 587 F. Supp. 1572 (E.D. NY 1984), the court concluded that

> *no procedures exist that permit the purely objective determination that a student is emotionally disturbed or behaviorally disordered to an extent requiring special education placement.*

Because of the subjective nature of the label "emotionally disturbed," the consent decree in the *Lora* case requires professionals to leave a "paper trail" describing the activities leading to their decisions on a label as well as the decisions themselves.

In another case, *Conejo Valley Unified School District*, 1985-86 EHLR DEC. 507:213, the hearing officer described socially maladjusted teenagers as follows:

> *The socially maladjusted teen is characterized by inability to tolerate structure, marked dislike of school, behavior beyond the control of parents, drug abuse, poor tolerance of frustration, excessive need for immediate gratification, disregard or hostility towards authority figures, lack of social judgment, inconsistent performance, positive behavior response when strong structure is instituted and lack of pervasiveness of disorder.*

According to the hearing officer, a seriously emotionally disturbed teenager may have some of these same characteristics, but they would be "intense and pervasive" and would be manifested to a marked degree and over a long period of time.

Determining whether a child is socially maladjusted or seriously emotionally disturbed requires expert professional judgment and careful analysis and documentation. It is important, as a parent, for you to know what steps the professionals are taking to document your child's proposed label and whether they are using appropriate standards.

WHAT IS THE DIFFERENCE BETWEEN SED AND BD?

The terms "seriously emotionally disturbed" and "behaviorally disordered" (BD), are often used interchangeably to refer to the same population. Some have suggested that "behaviorally disordered" is a more neutral term, carrying with it less of a stigma. Others suggest that "seriously emotionally disturbed" is a more descriptive term because it identifies a more severely affected group. The U. S. Department of Education commissioned a study of the two terms with a view to changing the terminology in P.L. 94-142 from "seriously emotionally disturbed" to "behaviorally disordered." This study concluded that changing the terminology would not solve the overall problem of making the definition more precise or more useable.

The current federal regulations for P.L. 94-142 allow states a great deal of freedom to determine how severe a student's problems must be for the student to be eligible to receive services. This latitude contributes to major inconsistencies in identification of emotionally disturbed students from state to state.

DOES A STUDENT WHO IS DIAGNOSED AS MENTALLY ILL BY A PHYSICIAN QUALIFY FOR SERVICES UNDER P.L. 94-142?

A physician's diagnosis alone does not qualify a student for services under P. L. 94-142. Because P.L. 94-142 is an education law, services are provided to children under this law only if their handicap interferes with their ability to do school work. To qualify a child for services, it must be demonstrated that he or she is handicapped and that the handicap interferes with the student's ability to benefit from education. A doctor's diagnosis must be given due consideration in deciding whether the child is handicapped in an educational sense, but other factors must be considered as well.

Some children with emotional problems continue to do well academically. Though they are in need of counseling or other types of help, they may not require those services to benefit from their education.

P.L. 94-142 is not intended to provide treatment for children. Instead, it is a guarantee that those children whose handicaps interfere with their education receive appropriate services to help them benefit from schooling.

IS PSYCHOTHERAPY A RELATED SERVICE?

This is a highly controversial question which has generated considerable legal action. Part of the problem is defining psychotherapy. If psychotherapy is defined narrowly to mean the treatment of emotional disorders by psychoanalytic methods, then provision of psychotherapy may imply having the services of a psychiatrist. Since psychiatrists are medical doctors, psychotherapy in this sense can be considered a medical service and thus not an allowable related service, except for diagnostic purposes, under P.L. 94-142.

If, on the other hand, psychotherapy is defined more broadly to mean therapy for psychological problems, then it could be a related service provided by nonmedical professional staff like a school psychologist, guidance counselor or social worker.

Another consideration is the intensity of therapy which is required. Related services are intended to supplement a student's education. If a child requires intense psychotherapy over a long period of time, that child may be a candidate for residential treatment which raises a whole set of other questions.

In summary, it appears that psychotherapy can be a related service if a child requires such therapy to benefit from his or her education, if such service can be provided by nonmedical professional staff, and if such therapy is a support to, rather than the main element of, a child's special education program.

WHAT RIGHTS DO STUDENTS HAVE IN THE SPECIAL EDUCATION PROCESS?

According to Section 504 and the Education for All Handicapped Children Act and its regulations, handicapped children have the right to:

1. A free and appropriate public education (FAPE) from the age of 6 through 18. (Many states also provide services to preschoolers and to students past the age of 18);

2. Access to the same variety of programs and services that children without handicaps enjoy, including non-academic subjects and extra-curricular activities;

3. Placement in the least restrictive learning environment, as much as possible at the same school they would attend if not handicapped;

4. The availability of an appropriate learning setting if attending a local public school is not possible;

5. The appointment of a person to act as a parent surrogate, and to participate in assessment and Individualized Education Program meetings with the school if natural parents are unavailable or if the child is a ward of the state;

6. Participation in the writing of their own Individualized Education Programs;

7. Placement outside the school district in another public school or private school at public expense if local schools do not have an appropriate or available program;

8. Testing for purposes of assessment and placement that is free of racial or cultural discrimination;

9. Annual review of placement based on an IEP;

10. Remain in present placement during administrative or judicial proceedings, or the right to attend a public school if the complaint involves an application for admission to public school;

11. Privacy and confidentiality of all personal records.

WHAT RIGHTS DO PARENTS HAVE IN THE SPECIAL EDUCATION PROCESS?

Under the Education of All Handicapped Children Act, as parents of a handicapped child, you have the right to:

1. Participate in the annual review of your child's Individualized Education Program (IEP);

2. Agree to a time and place for those meetings;

3. Instruct the local school agency to hold those meetings in your primary language, and to make special arrangements for your handicap, if any, so that you can understand the proceedings (example: providing an interpreter for hearing impaired parents);

4. Give your consent before an assessment is conducted;

5. Receive a copy of the assessment report;

6. Seek an independent assessment of your child at public expense if you find the school's assessment inappropriate. The school may request a hearing to decide the appropriateness of its assessment. If the ruling is in the school's favor, you still have the right to submit an independent assessment which must be considered but which is conducted at your expense;

7. Give voluntary written consent to any activities proposed for your child;

8. Have written notice of any proposed change or the school's refusal to make a change in identification, assessment, or placement of your child;

9. Attend and comment at the annual public hearing which must be publicized and held prior to adoption of the state plan for special education;

10. Review and, if necessary, question your child's records in accordance with the Family Educational Rights and Privacy Act of 1974;

11. Disagree and refuse consent on the following issues:

    a. Correcting or changing information in your child's files;
    b. Evaluating your child;
    c. Placing your child in a special education program;
    d. Obtaining additional information from an outside source about your child;
    e. Giving information from the school to another person about your child;
    f. Changing the special program placement of your child;
    g. Removing your child from the special education program;

12. Request a due process hearing on any proposal to initiate or change:

    a. the identification, assessment, or placement of your child;
    b. the provision of a free appropriate public education for your child; or
    c. the agency's refusal to do these things.

    (To request a hearing, you must write a letter to your local school explaining your concerns and your desire for a hearing.)

13. If the due process hearing does not produce a favorable result, you have the right to appeal to the next administrative level (state education agency) and/or to initiate civil action in the courts; and

14. Expect that information about your child will be kept private. No one may see your child's special education records unless you give your permission in writing. The only people who do not need that permission in writing are teachers and other school personnel who are planning your child's educational program or monitoring compliance with P.L. 94-142.

CAN PARENTS OR FAMILY MEMBERS BE REQUIRED TO RECEIVE COUNSELING IN ORDER FOR A CHILD TO RECEIVE SPECIAL EDUCATION?

Parents whose children have emotional disturbances cannot be required by the school district to undergo counseling. The child who qualifies for special education is entitled to an appropriate, individualized educational program without regard to what the parents do or do not do. Parents must be included in the development of the Individualized Education Program (IEP), but they cannot be required to participate or to do anything else which is not required of other parents with children in school. On a voluntary basis, parents may wish to seek counseling or to coordinate family counseling with the special education program at school.

FROM A LEGAL STANDPOINT, HOW IMPORTANT IS THE INDIVIDUALIZED EDUCATION PROGRAM?

In the years since the passage of the Education for All Handicapped Children Act the courts have held school districts accountable for providing the services and the type of placement indicated in the Individualized Education Program. School districts must make good faith efforts to implement the IEP. To insure that the IEP contains all that it should, parents must monitor the document carefully and must visit the classroom to make sure that the IEP is being implemented as planned.

WHAT SHOULD BE IN AN INDIVIDUALIZED EDUCATION PROGRAM?

An IEP must include:

1. A statement of the child's current level of educational performance;
2. Annual goals;
3. Short-term objectives to reach the annual goals;
4. A description of the services to be provided;
5. An explanation of the extent to which the child will participate in regular educational programs;
6. The projected date to begin services and the anticipated duration of services;
7. Criteria for determining, at least annually, whether goals and objectives have been achieved.

WHAT DOES "LEAST RESTRICTIVE ENVIRONMENT" MEAN?

Services to the handicapped child must be offered in a setting which deviates the least from the regular non-handicapped program and which is still appropriate for the child. In preparing P.L. 94-142, Congress recognized the need for handicapped children to be exposed to normal environments. Therefore, the law requires that handicapped children be educated to the maximum extent possible with non-handicapped peers, and if at all possible, in their neighborhood school.

HOW DOES LRE DIFFER FROM MAINSTREAMING?

Much confusion has arisen because the concept of least restrictive environment (LRE) is sometimes equated with mainstreaming. Mainstreaming, which means placing a handicapped child in the regular classroom, is actually not mentioned in P.L. 94-142. The law does not require that every handicapped child be placed in the regular classroom. Rather, the law says that to avoid placing children in settings that are too restrictive, school districts must provide a full range of options to meet the varying needs of handicapped children. The placement in special education must be determined for each child on an individual basis and according to that child's needs.

When determining an appropriate placement, prime consideration must be given to placing the child in the setting which is closest to normal and which still meets the child's needs. For some children the least restrictive environment will be the regular classroom. For others LRE may mean the resource room or a self-contained class. The point is that each child's case must be considered individually, and each child must be placed in an environment that is the least restrictive and most socially integrated that he or she can manage.

WHAT SHOULD PARENTS DO WHO THINK THEIR CHILD'S SPECIAL EDUCATION PROGRAM IS INADEQUATE?

If you think that your child's program is inadequate, ask for an IEP meeting to discuss the program and come up with a plan to remedy deficiencies. However, do remember that P.L. 94-142 guarantees an appropriate educational program, not the best possible one. You and the school district may disagree about whether the program being offered is appropriate. You may think that the school district is doing too little. School officials may contend that you are asking for too much. If you cannot settle your disagreement on an informal basis or through mediation, it may be necessary to go to a due process hearing.

WHAT IS A DUE PROCESS HEARING?

A due process hearing is a formal legal proceeding presided over by an impartial hearing officer who listens to both sides of the dispute and renders a decision based upon the law. To request a due process hearing, submit your request and a written copy of your concerns to the school board and superintendent of your school district.

WHO PAYS WHEN THERE IS A DUE PROCESS HEARING OR WHEN A SPECIAL EDUCATION CASE GOES TO COURT?

Due process hearings are held at public expense. In a court action, the judge may award the cost of reasonable attorney's fees to parents of a handicapped child if they are the prevailing parties in the case.

SECTION THREE: SCHOOL AND TREATMENT PROBLEMS

MAY A STUDENT WITH A SERIOUS EMOTIONAL DISTURBANCE BE EXCLUDED FROM SCHOOL?

P.L. 94-142 clearly forbids the exclusion of handicapped children from school. Regardless of the type or severity of handicap, handicapped children cannot be denied access to a free appropriate public education. In the case of disruptive students, the courts have said that schools may not totally exclude students whose handicaps have caused them to be disruptive. Rather schools have the duty to place handicapped students appropriately so that their behaviors can be properly controlled. During the time that school officials are seeking suitable placements, schools may refuse to admit students who may be a danger to themselves or others. *Jackson v. Franklin County School Board*, 76F. 2d 535 (5th Cir. 1985).

Thus, for a short period of time, schools may deny a child entrance while arrangements are being made for a suitable placement. However, such a child may not be denied admission to a school program and parents must give their consent before a child is placed. In addition, parents have the right to protest undue delay or to disagree with the placement decision.

CAN A SPECIAL EDUCATION STUDENT BE SUSPENDED OR EXPELLED FROM SCHOOL?

The discipline of handicapped students has emerged as one of the more controversial issues since the implementation of the Education for All Handicapped Children Act. Neither the act nor its regulations address the discipline issue directly, but many provisions have implications for the application of disciplinary policies to handicapped children. In general, as the courts have interpreted the act, they have upheld the authority of school officials to maintain order and discipline, while at the same time saying that the law cannot be circumvented through disciplinary policies. A balance has to be struck between the need of school authorities to maintain discipline and the rights of seriously emotionally distured students to obtain an appropriate education.

SHORT-TERM SUSPENSION. Handicapped students are neither immune from a school's disciplinary process nor are they entitled to participate in programs when their behavior impairs the education of other children in the program. Handicapped children who pose an immediate threat to the safety of others may be suspended for a maximum of ten school days. Suspensions in excess of ten days constitute a prohibited "change in placement." Indefinite suspensions are prohibited as they have the effect of excluding the student from the educational process. *Honig v. Doe*, 56 U.S.L.W. 4091 (1/20/88).

Parents and the student must be given notice of the charges for which suspension is the disciplinary action, and the student must be afforded a hearing on the charges. Further, suspension should trigger a complete review of the student's

Individualized Education Program to determine if the student's current placement is appropriate.

While proceedings are underway to review proposed placement changes, school officials are barred from changing a disruptive or dangerous student's placement. They may discipline a child by using such tools as study carrels, time-outs, detention, the restriction of privileges, or a maximum ten day suspension. The child may only be removed from his or her current educational placement for more than ten days if the parents agree, or if school officials demonstrate that "maintaining the student in his or her current placement is substantially likely to result in injury either to himself or herself, or to others." *Honig v. Doe*, 56 U.S.L.W. 4091 at 4097.

LONG-TERM EXPULSION. The Education for All Handicapped Children Act has been interpreted to provide that schools cannot expel students whose handicaps caused them to be disruptive. Rather, schools have the duty to place students appropriately, so that their behavior can be managed. However, the act does not prohibit all expulsions of disruptive handicapped children. It only prohibits expulsion of handicapped students who are disruptive because of their handicap. Whether a handicapped child may be expelled because of his disruptive behavior depends on the reason for the disruptive behavior. If the cause of the misbehavior is not the child's handicap and there is just cause for disciplinary action, then the child can be expelled. *Doe v. Koger*, 480 F. Supp. 225 (N.D. Ind 1979).

Before a handicapped student can be expelled, a trained and knowledgeable group of persons must determine whether the student's misconduct bears a relationship to his/her handicapping condition. For a handicap to be considered the cause of the misbehavior, the link between the handicap and the behavior must be direct. The argument that the handicap caused frustration which caused the misbehavior has not been persuasive to the courts.

In addition, if the school system is considering expelling a handicapped student, he or she must be afforded the following due process rights:

1. notice of charges;
2. notification of parents;
3. legal counsel;
4. the opportunity to confront and cross-examine witnesses and accusers;
5. a transcript of the proceedings; and
6. the opportunity to appeal.

Expulsion is considered a change in placement. Thus, the decision to expel, since it is a change in placement, requires the calling of an IEP meeting and a decision from the team about a more suitable educational placement for the student. If due process procedures are followed, a handicapped student may be expelled for just cause, but expulsion of that student cannot lead to a complete cessation of education services. *S-1 v. Turlington*, 635 F. 2d 342 (5th Cir. 1981),cert. den. 454 US 1030 (1981).

IS CORPORAL PUNISHMENT PERMISSIBLE?

P.L. 94-142 does not address corporal punishment as an issue. In general, corporal punishment is a matter for state law and school district policy. It is wise for parents to investigate local laws and policies on this issue. In addition, parents should find out if the local district has policies about aversive procedures like physical restraint and seclusion (time out). Disciplinary measures which are contemplated can and should be written into the IEP, especially if they differ from the usual procedures followed for other children in the school. Just as with any aspect of the IEP, if parents do not agree with the special disciplinary measures proposed by the school district, they can submit the disagreement to mediation or due process hearing.

DOES A STUDENT WITH A DRUG OR ALCOHOL PROBLEM QUALIFY FOR SPECIAL EDUCATION?

Drug addiction and chemical dependency are not mentioned as handicapping conditions under P.L. 94-142. In general, students with these types of problems have not been served in special education unless they meet the criteria for one of the handicapping conditions like learning disabilities or emotional disturbance.

Some school districts have served chemically dependent students when they are in treatment by placing them in the category of "other health impaired." Under these circumstances the student receives instruction from an itinerant teacher in the same way that hospitalized students with other types of illnesses are served. Providing services to hospitalized students assumes that the school district recognizes chemical dependency as an illness.

Special education services to chemically dependent students raise a number of questions which, at this point, remain largely unclarified. Parents may want to bring the following issues to the attention of their local school district and/or state education agency:

Do school districts provide homebound services for the chemically dependent student who is:

1. Homebound and under medical treatment or doctor's orders;
2. Residing in a residential treatment center;
3. Placed out-of-district at a residential home, school or treatment center for the chemically dependent;
4. An outpatient at a treatment center?

If homebound services are provided, how long do they last?

When a student returns from treatment, what services are provided to help him or her catch up with academic work?

Does the school district have any obligation to provide remedial services?

DOES SECTION 504 REQUIRE SPECIAL EDUCATION FOR CHEMICALLY DEPENDENT STUDENTS?

The question of whether Section 504 requires the provision of special education services to chemically dependent students is as yet unresolved. However, there is an interesting case which has arisen in the State of Washington, that may affect the relationship of chemically dependent students and special education. *Lake Washington School District No. 414*, Case No. 10841039, OCR Region X, Letter of Findings 6/28/85. In this case, the parents filed a complaint with the Office of Civil Rights claiming that their son, who was chemically dependent and had received treatment, was not being offered an appropriate education. Consequently, the parents claimed they were forced to make out-of-district placement for which the district should be obligated to pay.

The Lake Washington School District claimed that it was not required to evaluate this student or pay for his out-of-district treatment program because he was not believed to be handicapped within the meaning of the Education of All Handicapped Children Act.

The Office of Civil Rights ruled that the district's failure to recognize the student as handicapped and its consequent failure to evaluate him for the purpose of determining his individual educational needs, despite teachers' beliefs that his needs were not being met, was a violation of the student's rights under Section 504 of the Rehabilitation Act of 1973.

Alcoholics and drug addicts are qualified handicapped persons within the meaning of Section 504 if their physical impairments substantially limit one or more major life activities, even if they are not handicapped within the meaning of EHA. Furthermore, the district erred in failing to notify the parents of their rights and the district's duties under Section 504. However, the Office of Civil Rights did not require the district to assume costs of out-of-district placement because, *prior* to placing the student, the parents neither requested that the district place him out of district nor asked the district to pay tuition. The Lake Washington case suggests that, even though chemically dependent students do not qualify for services under EHA, they may qualify for some services under Section 504.

MUST SCHOOL DISTRICTS PAY FOR RESIDENTIAL TREATMENT FOR STUDENTS WITH EMOTIONAL DISTURBANCES?

School districts are obligated to provide appropriate educational programs for qualifying special education students. If the school district can serve a child with an emotional disturbance in a nonresidential school program which is appropriate for the child, then the school district is not obligated to pay for a residential program simply because the parents would prefer that program.

The question becomes whether the program the school district is offering is, in fact, *appropriate* to meet the child's needs. If there is disagreement about the appropriateness of the program, the matter can be taken to a due process hearing. If the hearings officer rules that the school program is not appropriate and that a residential placement would be appropriate, then the school must bear the cost of that placement.

If parents make the decision on their own to place a child in a residential treatment program, the school district cannot be held responsible for the cost of that placement unless it can be demonstrated that the school district had no suitable placement. Again, the determination about whether the school district has a suitable placement may have to be made in a due process hearing. P.L. 94-142 provides:

> *Disagreements between a parent and a public agency regarding the availability of a program appropriate for the child, and the question of financial responsibility, are subject to the due process procedure.*

DOES A PARENT HAVE TO GIVE UP CUSTODY IN ORDER FOR A CHILD TO RECEIVE RESIDENTIAL CARE?

When a child requires residential treatment, obtaining treatment can be an enormous problem for parents because of the high cost. Very few families have the financial resources themselves to pay for even a short stay in a treatment center. Some families do have health insurance which covers part, but seldom all, of the costs. For those families without insurance and with limited financial means, the only way they can obtain residential treatment for their children may be to turn to the state for help.

In many states, state agencies will not pay for residential treatment unless the child has been adjudicated a ward of the court. In other words, the state agencies may agree that residential treatment is desirable, but they will not pay for such treatment unless forced to do so by the courts. In these situations, parents are sometimes left with no choice, but to give up custody of the child so that he or she can come under the protection of the courts and receive treatment.

WHAT DOES "ADJUDICATED" MEAN?

In this context, "adjudicated" means coming under the protection or guardianship of the court. Court guardianship can be continued for an indefinite period of time and can be useful in obtaining services for a child who is emotionally disturbed. Although children's courts usually rely on recommendations or changes suggested by caseworkers or state agencies, the courts can also implement therapeutic and corrective actions of their own. Courts may stipulate attendance in a vocational or trade school, treatment by psychotherapy, the assignment of a caseworker to work with parents, placement in a foster home or children's residential treatment center, or commitment to a psychiatric hospital or correctional institution.

When a child has been adjudicated, there is no question that parents lose decision-making powers on behalf of the child. Parents may contest court decisions, but the courts usually have the support of other legal agencies and often may impose even more stringent consequences in reviewing their decisions.

UNDER WHAT CIRCUMSTANCES DO PARENTS LOSE CUSTODY?

Parents can lose custody of their children if it is demonstrated that those children suffer from abuse and neglect. More than 40 states have "protective services" whose responsibility is to deal with cases of neglect and abuse of children. Protective services investigate reports of child abuse and advise the courts when there is evidence that abuse exists. Usually parents are offered an opportunity to remedy the abuse situation. If the parent refuses to cooperate or the abusive situation is not redeemable or is immediately dangerous, the abused child can be removed from the home and legal proceedings can be initiated against the parents.

In child abuse cases, the judge has the power to interpret such vague conditions as "proper care" and situations "prejudicial to the child's well-being." In general, courts have agreed that a parent has a right to live as he or she pleases within broad limits; that is, the parent need not have a job, be married to the person he or she lives with, or spend his/her money on the family. Courts have decreed that the rights of each citizen include the freedom to marry, establish a home, bring up children, and enjoy privacy. However, the parent does not have the right to deprive children of the necessities of life, abuse them physically or emotionally or deny them treatment they require.

The federal Child Abuse and Treatment Act, (P.L. 93-247) defines child abuse and neglect as

> *any physical or mental injury, sexual abuse, negligent treatment or maltreatment of a child under the age of 18 by a person who is responsible for the child's welfare.*

If there is evidence of child abuse and neglect and parents refuse to comply with efforts to improve the situation, the parents may lose custody of their children. Under these circumstances, the courts assume responsibility for assuring that the children receive treatment for their abuse and neglect as well as foster or residential care.

WHEN A CHILD IS SENT TO A CORRECTIONAL FACILITY, WHAT RIGHTS DOES THE CHILD HAVE?

The answer to this question varies somewhat from state to state. However, because P.L. 94-142 is a federal law its provisions apply to children throughout the United States. Any child who is of school age and who is determined to be handicapped must receive a free appropriate public education, regardless of whether that child is in a correctional facility. So a child in a state correctional facility who qualifies for special education should receive that education during his or her stay at the training school. If the child is a ward of the state (which is often the case in these situations), a surrogate parent can be appointed to represent his or her interests in the special education process. Parents who wish to be involved also may be included.

HOW CAN A CHILD BE PLACED IN A STATE PSYCHIATRIC INSTITUTION?

Placement in a state institution usually involves a court order for voluntary or involuntary commitment or an emergency order for evaluation or protective custody. Laws vary widely from state to state about how commitment takes place. Generally, however, the following guidelines appear in most states:

EMERGENCY ADMISSION. If a person believed to be seriously emotionally disturbed poses a threat of death or serious bodily harm to himself or others, that person may be admitted to a state institution on an emergency basis. As quickly as possible, formal legal steps must be taken to seek the person's admission for evaluation and treatment. An emergency admission may last only as long as necessary to protect the person and obtain court approval for commitment or some other form of treatment.

INVOLUNTARY ADMISSION. A parent, mental health professional, lawyer or physician can petition the court to have an individual committed to a mental institution. If the court decides there is merit in the petition, the individual must be evaluated to determine if mental illness is present. Then a hearing must be held to present the results of the evaluation. During the proceedings, the individual's interests should be represented by an advocate and/or lawyer. If the court decides that the evidence of mental illness and need for treatment is compelling, then the court can order an involuntary commitment. In some states the period of commitment is limited to six months or one year and an automatic review of the patient's status is ordered at the end of that time.

VOLUNTARY ADMISSION. An individual may voluntarily request evaluation for mental illness and admission to a state institution. Once again, this is a legal proceeding, and the individual making the request should be represented by counsel.

SOURCES OF INFORMATION ABOUT MENTAL HEALTH ISSUES

American Association of Psychiatric
Services for Children
1725 K Street, N.W.
Washington, D.C. 20006
(202) 659-9115

Federation for Children with
Special Needs
312 Stuart Street, Second Floor
Boston, MA 02116
(617) 482-2915

Institute for Child Behavior
Research
4157 Adams Avenue
San Diego, CA 92116
(714) 281-7165

Mental Health Law Project
1220 19th Street, N.W.
Suite 300
Washington, D.C. 20036
(202) 467-5730

National Alliance for the Mentally Ill
1901 N. Ft. Myer Drive, Suite 500
Arlington, VA 22209
(703) 524-7600

National Clearinghouse for Mental
Health Information
National Institute of Mental Health
11A-33 Parklawn Building
5600 Fishers Lane
Rockville, MD 20857
(301) 443-4513

National Information Center for
Handicapped Children and Youth
Box 1492
Washington, D.C. 20013
(703) 522-3332

National Mental Health Association
1800 North Kent Street
Arlington, VA 22209
(703) 528-6405

National Society for Children and Adults
with Autism
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, D.C. 20005
(202) 783-0125

The Information Exchange on Young
Adult Chronic Patients, Inc.
P.O. Box 1945
New City, New York 10956
(914) 634-0050

Information about parent groups across the United States that provide support, information, advocacy and other services to parents is provided in the *National Directory of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth.* The directory is available from the following:

Families as Allies Project
Research and Training Center
Regional Research Institute
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(503) 464-4040

EXERCISES

QUESTIONS

The following exercises provide an opportunity for you to think about what you have read in this chapter. The page numbers for each exercise indicate the section of the text on which the questions are based.

EXERCISE Section 1 Number 1 (pp. 61-62)

Match the following terms with the definitions listed below.

______ 1. Autism

______ 2. Behavior Disorder

______ 3. Brain Injured

______ 4. Delinquent

______ 5. Deviant

______ 6. Emotionally Disturbed

______ 7. Mentally Ill

______ 8. Neurologically Impaired

______ 9. Sociopath

______10. Social Maladjusted

A. A child who has been found by a court of law to have violated a law.

B. Suffering from extreme disturbance of the emotional process.

C. Displaying extreme disregard for and hostility toward society.

D. Suffering from a psychological illness.

E. Having a damaged nervous system.

F. Physical harm to the brain resulting in impaired function.

G. A condition characterized by extreme lack of ability to communicate and to form human relationships.

H. Having difficulty dealing with society and groups of people.

I. An individual who breaks rules, particuarly of a sexual nature.

J. Displaying behaviors which deviate significantly from socially accepted norms.

EXERCISE Section 1 Number 2 (pp. 61-62)

Answer the following questions in your own words.

1. What is the value of a diagnostic label?

2. What is the danger of an inappropriate label?

EXERCISE Section 2 Number 1 (pp. 63-71).

Identify the following initials.

1. FERPA

2. BD

3. SED

4. EHA

EXERCISE Section 2 Number 2 (pp. 63-71)

True of False.

T F 1. Under FERPA, parents have the right to request that school records be amended.

T F 2. Complaints charging discrimination under Section 504 must be lodged with the U.S. Department of Education.

T F 3. Schools may exclude seriously emotionally disturbed students if there are no programs for them.

T F 4. Related services must be provided if they are necessary for a student to benefit from his or her education.

T F 5. A child with schizophrenia would qualify for services under P.L. 94-142.

T F 6. In the *Lora* case, the court provided a precise, legal definition for "seriously emotionally disturbed."

T F 7. The terms SED and BD are often used interchangeably to identify the same population.

T F 8. Under P.L. 94-142, schools must seek out and identify all handicapped children.

T F 9. Parent counseling is a related service under EHA.

T F 10. Only the 13 items mentioned in EHA may be considered related services.

EXERCISE Section 2 Number 3 (pp. 63-71)

Fill in the blanks.

1. Seriously emotionally disturbed is a condition exhibiting one or more of the following characteristics over ______________________________ and to ______________________ which adversely affects __________ performance.

2. Under P.L. 94-142, the term "seriously emotionally disturbed," includes children who are ____________________ or ____________________. The term does not include children who are ______________________, unless it is determined that they are ____________________________.

EXERCISE Section 2 Number 4 (pp. 63-71)

List 3 rights that P.L. 94-142 guarantees to your child.

1.

2.

3.

List 3 rights that P.L. 94-142 gives you as a parent acting on behalf of your child.

1.

2.

3.

List the 7 parts of an Individualized Education Program.

1.

2.

3.

4.

5.

6.

7.

EXERCISE Section 2 Number 5 (pp. 63-71)

In your own words, define the following terms.

1. LRE

2. Mainstreaming

3. A due process hearing

EXERCISE Section 3 Number 1 (pp. 72-78)

Reread the section on suspension and expulsion and answer the following questions.

1. For how long may a special education student be suspended?

2. Under what circumstances is a school district prohibited from expelling a student?

3. Under what conditions may a special education student be expelled?

4. What due process rights does a student have when the school system is considering expulsion?

5. When may a school refuse to admit a student?

EXERCISE Section 3 Number 2 (pp. 72-78)

In the following circumstances, do the parents or the school district pay for the school placement?

________ 1. MARK attends a day treatment program in an elementary school in his district. Both his parents and school officials agreed to this placement in the Individualized Education Program.

________ 2. SALLY lives in a group home and attends school in school district A. Sally's parents have custody of her and live in school district B.

________ 3. FRANK attends a residential school for the emotionally disturbed. His parents placed him there when they became discouraged with the program in their local school district.

________ 4. MIKE's parents both have chronic illnesses and cannot care for him any longer. They want to place him in a private residential facility but cannot afford the total cost. The local school district serves Mike in a classroom with other children with handicaps.

________ 5. NIKKI's family lives on a ranch several miles from town. She is bused out of her rural school district (District R) to neighboring School District B for services in a self-contained class for the severely emotionally disturbed.

ANSWERS

HOW DID YOU DO? EXERCISE 1.1 (p. 81)

1. G
2. J
3. F
4. A
5. I
6. B
7. D
8. E
9. C
10. H

HOW DID YOU DO? Exercise 1.2 (p. 82)

1. A diagnostic label is useful if it truly describes the problem and leads to helpful treatment and/or educational solutions.

2. Mislabeling is dangerous because it sometimes leads to inappropriate treatment.

HOW DID YOU DO? Exercise 2.1 (p. 83)

1. Family Educational Rights and Privacy Act (FERPA)

2. Behaviorally Disordered (BD)

3. Seriously Emotionally Disturbed (SED)

4. The Education of All Handicapped Children Act (EHA)

HOW DID YOU DO? Exercise 2.2 (p. 83)

1. True
2. False
3. False
4. True
5. True
6. False
7. True
8. True
9. True
10. False

HOW DID YOU DO? Exercise 2.3 (p. 84)

1. A long period of time; a marked degree; educational

2. schizophrenic; autistic; socially maladjusted; seriously emotionally disturbed.

HOW DID YOU DO? Exercise 2.4 (p. 84)

Special needs children are guaranteed all of the following rights:

1. The right to an appropriate education, as defined by an Individualized Education Program;
2. The right to education in the least restrictive environment;
3. The right to due process hearings;
4. The right to nondiscriminatory evaluation;
5. The right to related services such as transportation or therapy.

Parents of children with special needs have the following rights:

1. The right to monitor testing and assessment of the child;
2. The right to examine and correct all records about the child;
3. The right to be involved in any meetings where decisions about the child's education will be made.

The seven parts of an IEP are:

1. Present level of education performance;
2. Annual goals;
3. Short-term objectives;
4. Statement of specific education and related services to be provided;
5. Description of the extent to which the child will participate in regular education programs and a description of the programs to be provided;
6. Projected dates for initiation of services and the anticipated duration of services;
7. Objective criteria and evaluation procedures.

HOW DID YOU DO? Exercise 2.5 (p. 85)

1. LRE is the placement of a special education student in the learning situation which is as close as possible to the typical school situation and which still meets the student's unique needs.

2. Mainstreaming is the placement of a special education student into the regular classroom or the regular education program.

3. A due process hearing is a hearing presided over by an impartial hearings officer in which parents and school district personnel have the opportunity to present their sides of a disagreement. The hearings officer renders a decision based upon an analysis of the law and the facts.

HOW DID YOU DO? Exercise 3.1 (p. 86)

1. 10 days

2. A school district may not expel a special education student, if it can be demonstrated that the student's misbehavior was a result of his or her handicapping condition.

3. A special education student may be expelled if the misbehavior is unrelated to the student's handicap, and if there is just cause for expulsion.

4. Due process rights include: notice of charges, notification of parents, right to legal counsel, right to confront and cross-examine witnesses and accusers, right to a transcript of the proceedings, and right to appeal.

5. During the time that school officials are seeking suitable placements, a school may refuse to admit a student who is dangerous to him or herself or to others.

HOW DID YOU DO? Exercise 3.2 (p. 86-87)

1. SCHOOL. Since the placement was agreed upon in the IEP, the cost of the placement is the school's responsibility.

2. SCHOOL DISTRICT A OR SCHOOL DISTRICT B. If School District B in which Sally's parents live is able to provide her with an appropriate program, then this home district could argue against having to pay for an out-of-district placement in School District A. The key question in deciding upon which district should pay is the agreement made at the time of the original placement. If the placement in the group home and in School District A was not made upon educational grounds, but to provide an appropriate residential placement, then School District B may not be liable for costs. However, if the placement in the group home and in School District A was based upon a need to find an appropriate educational placement, then School District B is liable for the educational costs of Sally's placement. State laws vary on this type of placement issue, and many states lack any legislation which addresses this type of problem.

3. PARENTS OR SCHOOL. The parents would have to pay for this placement, since they made the decision unilaterally, unless they can demonstrate in a due process hearing or in court that the school district does not have an appropriate placement available.

4. PARENTS. If the local district has an appropriate educational placement for Mike, the district does not have to pay for an out-of-district placement that is made on the basis of need for a change of residence. Again, state rules and regulations may vary on this type of issue.

5. SCHOOL DISTRICT R. If Nikki's home school district (District R) does not have an appropriate program for her, then District R must pay the costs of an out-of-district placement in School District B.

REFERENCES/BIBLIOGRAPHY

Ackerman, P. & Kappelman, M. (1977). *Between parent and school.* New York: The Dial Press.

Anderson, W., Chitwood, S., & Hayden, D. (1982). *Negotiating the special education maze.* Englewood Cliffs, N.J.: Prentice-Hall.

Biklen, D. (1974). *Let our children go: An organizing manual for advocates and parents.* Syracuse: Human Policy Press.

Brewer, G.D. & Kakalik, J.S. (1979). *Handicapped children: Strategies for improving services.* New York: McGraw-Hill.

Brown, S.L. & Moersch, M., (Eds.) (1978). *Parents on the Team.* Ann Arbor: University of Michigan Press.

Dinsmore, J. & Yohalem, D. (1978). *94-142 and 504: Numbers that add up to educational rights for handicapped children.* Washington D.C.: Children's Defense Fund of the Washington Research Project, Inc.

Fernandez, H. (1980). *The child advocacy handbook.* New York: Pilgrim Press.

How to organize an effective parent group and move bureaucracies. (1971). Chicago, Il.: Coordinating Council for Handicapped Children, 407 S. Dearborn, Chicago, Illinois, 60605.

Knitzer, J. (1982). *Unclaimed children: The failure of public responsibility to children and adolescents in need of mental health services.* Washington, D.C.: Children's Defense Fund.

Lillie, D.L. & Place, P.A. (1982). *Partners: A guide to working with schools for parents of children with special instructional needs.* New York: Scott-Foresman.

Martin, R. (1979). *Educating handicapped children: The legal mandate.* Champaign, IL: Research Press Company.

Moore, C.B. & Morton, K.G. (Eds.). *A reader's guide: For parents of children with mental, physical or emotional disabilities.* Rockville, MD: Publication #(HSA) 77-5290, Public Health Service, Health Services Administration, Bureau of Community Health Services.

Mopski, S.I. & Agard, J.A. (Eds.). (1979). *Parents and special education: A cooperative endeavor.* Cambridge, MA: ABT Books, Inc.

Slenkovich, J. (1984). *Understanding special education law.* Cupertino, CA: Kinghorn Press.

The rights and parents and the responsibilities of schools. (1978). Cambridge, MA: Education Publishing Service.

GLOSSARY

ACRONYMS

A&D	Alcohol and drug.
ACCH	Association for the Care of Children's Health. A multidisciplinary association of professionals and parents that promotes quality psychosocial health care for children and their families.
ACSW	Denotes certification by the academy of Certified Social Workers. Requires 3,000 hours of paid supervised work experience beyond the MSW and an examination. (Page 34)
ADD	Attention deficit disorder. See Attention-deficit Hyperactivity Disorder. (Page 26)
ADHD	Attention-deficit hyperactivity disorder. A condition characterized by a failure to remain attentive in various situations, especially in the school and home. (Page 26)
AMI	Alliance for the Mentally Ill. See NAMI.
ARC	Association for Retarded Citizens. Support group and program for families with children who are mentally retarded.
BD	Behavior disordered. (Page 62, 66)
CAN	Child abuse and neglect.
CAP	Center Accreditation Project. A national certification project for quality child care programs.
CASA	Court-appointed special advocate.
CASSP	Child and Adolescent Services System Program. Funded by the National Institute of Mental Health in 28 states and three local communities to plan, develop and implement services for children and adolescents with serious emotional impairments.
CCD	Crippled Children's Division. A program for children with physical impairments.
CDA	Child Development Associate. Training and certification program for Head Start and child care staff.
CEC	Council on Exceptional Children. Professional organization for persons serving exceptional school age children.

CMHC	Community Mental Health Center. A facility providing local mental health services. May be run by the county or state or be a private, non-profit organization.
CMI	Chronically mentally ill.
CP	Cerebral palsy.
CPS	Child Protective Services. State or county agency responsible for addressing issues of child abuse and neglect.
CSP	Community Support Program. Federally funded programs (through the National Institute of Mental Health) to develop community support systems for persons with longterm psychiatric disabilities.
CST	Child Study Team. A team consisting of the parents of a child with a handicap and professionals serving the child, convened to develop long and short range goals for the child's progress.
DD	Developmentally disabled (or delayed). Persons whose diagnosis may include mental retardation, epilepsy, autism, cerebral palsy or similar impairments. (See also MR/DD)
DEC	Division for Early Childhood of the Council for Exceptional Children. The professional organization for persons serving preschool children with handicaps.
DHHS	United States Department of Health and Human Services.
DOE	Department of Education (United States or state).
DSM III	Diagnostic and Statistical Manual of Mental Disorders (3rd Edition Revised). A classification system for mental illnesses developed by the American Psychiatric Association.
D.S.W.	Doctorate degree in social work. (Page 35)
ED	Emotionally disturbed.
Ed.D.	Indicates doctoral degree in Education.
EEG	Electroencephalogram. A test which measures electrical impulses in the brain. (Page 32)
EH	Emotionally handicapped.
EHA	The Education for All Handicapped Children Act. See Public Law 94-142.

FAA	Families as Allies Project, Research and Training Center, Portland State University, Portland, Oregon.
FAPE	A free and appropriate public education. (Page 67)
FERPA	Family Educational Rights and Privacy Act. (Student School Records Act.) Federal regulation governing confidentiality of student records and parental rights of access and consent to release. (Page 63)
I & R	Information and Referral.
ICFMR	Intermediate Care Facility for the Mentally Retarded.
IEP	Individualized Education Program. A written plan of services for a child with a handicap developed jointly by parents and school personnel as required under Public Law 94-142. (Page 69, 70)
IFSP	Individual Family Services Plan. Written objectives for each child 0-2, addressing both the child's and family's needs in the early intervention program.
LCSW	Denotes certification by a state as a licensed clinical social worker. Such licensure often requires at least two years experience with a direct client caseload under supervision. (See ACSW and RCSW) (Page 34)
LEA	Local Educational Agency.
LRE	Least Restrictive Environment. (Page 70, 71)
MBD	Minimal brain dysfunction. See Brain injured in the Terms section of the glossary.
MED	Mental or emotional disturbance (or disorder).
MHA	Mental Health Association. A non-profit citizens organization dedicated to legislative advocacy on behalf of the mentally ill and children with disturbances. Other services include public education and prevention of abuse and family problems and sponsorship of parent support groups.
MI	Mentally impaired/ill.
MMPI	Minnesota Multiphasic Personality Inventory. A personality assessment tool widely used in making psychological evaluations. Normally given to persons 16 years of age and older.
MPB	Migrant Program Branch. A federal Head Start program serving Native American children who reside on reservations and migrant children.
MPH	Indicates a master's degree in Public Health.
MR	Mentally retarded.

MR/DD	Mentally retarded/Developmentally disabled (or delayed).
M.S.W.	Master's degree in social work. (Page 35)
NAEYC	National Association for the Education of Young Children. A professional organization for persons in early childhood education.
NAMI	National Alliance for the Mentally Ill. A self-help organization of mentally ill persons, their families and friends.
NICCYH	National Information Center for Children and Youth with Handicaps. A free information service that assists parents, educators, caregivers and others in ensuring that all children and youth with disabilities have a better opportunity to reach their fullest potential.
NIDRR	National Institute on Disability and Rehabilitation Research. A federal agency that funds research and services for persons with physical or mental disabilities. Part of the United States Department of Education.
NIMH	National Institute of Mental Health. A federal agency, part of the United States Department of Health and Human Services that sponsors research and demonstration activities to increase knowledge and improve services in the field of mental health.
NMHA	National Mental Health Association. See MHA.
OT	Occupational therapy.
P & A	Protection and Advocacy. State agency providing advocacy activities on behalf of persons with developmental disabilities and mental illness. See Public Law 99-319.
PDD	Pervasive developmental disorder.
Ph.D.	Indicates a doctoral degree in any of a wide range of disciplines (sociology, psychology, anthropology, mathematics, etc.)
PIC	Parent Information Center. Parent information and support programs funded by the United States Department of Education.
PT	Physical therapy.
PTI	Parent Training and Information Centers. See PIC.
R & R	Resource and referral.
R & T	Research and Training Centers (or R & T Centers). Thirty-six centers funded by NIDRR to provide research, training and technical assistance to consumers with disabilities and service providers. Two centers focus on the needs of children and youth with emotional handicaps. These

two centers are also supported by NIMH and are located at the University of South Florida and at Portland State University in Oregon.

RCSW	Denotes certification by a state as a registered clinical social worker. Such licensure often requires at least two years supervised experience with a direct client caseload. (See also ACSW and LCSW) (Page 34)
RN	Registered nurse. (Page 35)
RRC	Regional Resource Centers. Federally funded programs responsible for training and technical assistance to staff who serve school age children with handicaps.
RRI	Regional Research Institute for Human Services. Portland State University, Portland, Oregon.
SAT	Standardized achievement test.
SEA	State educational agency.
SED	Seriously emotionally disturbed. Also commonly EH for "emotionally handicapped."
SMHRCY	State Mental Health Representatives for Children and Youth. The professional people in each state responsible for the planning, development and management of public child mental health services. A division of the National Association of State Mental Health Program Directors.
SS	Social services.
SSA	Social Security Administration. A federal agency that administers social security and disability benefits.
SSDI	Social Security Disability Insurance. A federal program administered by SSA.
SSI	Supplemental Security Income. A federal program administered by SSA.
VR	Vocational Rehabilitation. Also commonly VRD or DVR; "D" for Department.
WISC	See Wechsler Tests in Terms section of glossary.
WRAT	Wide Range Achievement Test. A short test for evaluating basic skills of spelling, arithmetic and reading. The WRAT is widely used by schools for testing educational achievement.

LAWS AND REGULATIONS

Public Law (P.L.) 94-142	The Education for All Handicapped Children Act. A federal law which guarantees a free, appropriate public education for all children with handicaps. Also known as 94-142.
Public Law (P.L.) 94-457	1986 Amendments to Education for All Handicapped Children Act. A federal law providing free and appropriate education and "related services" to preschool age children with handicaps.
Public Law (P.L.) 96-272	Adoption Assistance and Child Welfare Act of 1980. Federal law outlining procedures for the placement of children out of home by state child welfare agencies.
Public Law (P.L.) 96-398	Mental Health Systems Act. (1980) Encourages the development of systems of care. Policies contained in the Act received no specific funding.
Public Law (P.L.) 99-319	Protection and Advocacy for Mentally Ill Individuals Act of 1986.Federal law allocating funds to each state for advocacy activities on behalf of persons with developmental disabilities or mental illness.
Section 504	A part of the Rehabilitation Act of 1974. This section states that no program or activity receiving federal funds can exclude, deny benefits to, or discriminate against any person on the basis of handicap. It also requires access for people who are handicapped to all public buildings. Also known as 504.
Title XIX (19)	Federal program of medical aid designed for those unable to afford fee for service medical care. (Medicaid). With a Medicaid card, individuals can purchase medical service as needed in the community. Part of the Social Security Act.
Title XX (20)	Federal program supports social services at the state and local level contingent on the development of a plan which includes the goals and target groups for such services. Part of the Social Security Act.

TERMS

Acting Out	Self-abusive, aggressive, violent and/or disruptive behavior. (Page 3)
Acute	Marked by a sudden onset, sharp rise, and lasting a short time, demanding urgent attention
Adjudicated	Coming under the protection or guardianship and jurisdiction of the court. (Page 76)
Adjustment Disorder	Maladaptive reaction in adolescents to an identifiable source. (Page 29)
Advocacy	The process of actively supporting the cause of an individual (case advocacy) or group (class advocacy), speaking or writing in favor of, or being intercessor or defender. Action to assure the best possible services for or intervention in the service system on behalf of an individual or group. (Page 12, 13)
Affect	Feeling, emotion.
Affective	Related to or arising from feelings and emotions. (Page 27)
Affective Disorder	A disorder of mood (feeling, emotion). Refers to a disturbance of mood and other symptoms that occur together for a minimal duration of time and are not due to other physical or mental illness. (Page 28)
Anxiety Disorder	Exaggerated or inappropriate responses to the perception of internal or external dangers. (Page 27)
Appropriate Education	An individual education program specially designed to meet the unique needs of a child who has a handicap. (Page 64)
Assessment	See Evaluation.
Autistic Disorder	A disorder (usually appearing by age 2) characterized by lack of communication, lack of social skills, withdrawal and developmental delays. (Page 28, 61)

Avoidant Disorder	Avoiding the establishment of new interpersonal contacts to the extent that social functioning is impaired. (Page 27)
Behavior Disordered	Displaying behaviors over a long period of time which significantly deviate from socially acceptable norms for the individual's age and situation. (Page 62, 66)
Bipolar Disorder	A mood disorder with elevated mood, usually accompanied by a major depressive episode. (Page 28)
Brain-Injured	A condition in which an individual before, during, or after birth has received an injury to or suffered an infection of the brain. As a result of such organic impairment, there may be disturbances that prevent or impede the normal learning process. (Page 62)
Case Management	A service that assists clients to obtain and coordinate community resources such as income assistance, education, housing, medical care, treatment, vocational preparation, and recreation.
Case Manager	An individual who organizes services for a client.
Child Psychiatrist	A physician (M.D.) specializing in mental, emotional, or behavior disorders in children and adolescents. Qualified to prescribe medications. (Page 34)
Child Psychologist	Indicates a mental health professional with a Ph.D. in psychology who administer tests, evaluates and treats children's emotional disorders. Cannot prescribe medication. See Psychiatrist.
Child Welfare	A field of social service concerned with the care and well being of children.
Child Welfare Agency	An administrative organization providing protection to children, and supportive services to children and their families.
Childhood Depression	See Major Depressive Episode.
Chronic	Marked by long duration or frequent recurrence.

Clinical Psychologist	A mental health professional trained to administer psychological tests, evaluate and treat emotional disorders. Cannot prescribe medication. See Psychiatrist. (Page 34)
Clinical Social Worker	A mental health professional trained to provide services to individuals, families, and groups. Cannot prescribe medication. See Psychiatrist. (Page 35)
Community Support System	An organized system of care to assist adults with long-term psychiatric disabilities to meet their needs and develop their potentials without being unnecessarily isolated or excluded from the community.
Conduct Disorder	Repetitive and persistent patterns of behavior that violate either the rights of others or age appropriate social norms or rules. (Page 26)
Day Treatment	Community based, non-residential program of services for children. It is the most intensive program available that still allows the child to remain in the home. (Page 38)
Defensive Behavior	Behavior that is for the purpose of protecting the individual or avoiding unpleasant ideas, thoughts, and consequences. (Page 3)
Delinquent	A child or youth (usually under 18) who is found by a juvenile court to have broken a law. (Page 62)
Deviant Behavior	Breaking formal or informal rules or laws relative to social customs or norms, including sexual behavior. (Page 62)
Due Process Hearing	A formal legal proceeding presided over by an impartial public official who listens to both sides of the dispute and renders a decision based upon the law. (Page 71)
Emotionally Disturbed or Emotionally Handicapped	A child or adolescent who exhibits behavioral, emotional and/or social impairment that consequently disrupts the child's or adolescent's academic and/or developmental progress, family, and/or interpersonal relationships. (Page 62, 64, 65)

Evaluation	A process conducted by mental health professionals which results in an opinion about a child's mental or emotional capacity, and may include recommendations about treatment or placement. See Assessment.
Exceptional Children	Children whose performance deviates from the norm (either above or below) to the extent that special programming is needed.
Family Support Program	Programs available in the community that assist children and their families so that children can remain in their homes.
Family Therapy	A treatment model that involves interaction with family members and family interactions as well as with the individual. (Page 25)
Guidance Counselor	An individual working in a school who is trained to do screening, evaluations, and career and academic advising. (Page 35)
Hyperactivity	Excessive movement or activity. A feature of Attention-deficit Hyperactivity Disorder. (Page 26)
Identity Disorder	Severe subjective distress caused by child's inability to achieve an integrated sense of self. (Page 29)
Individualized Education Program (IEP)	A written plan of services for a child with a handicap developed jointly by parents and school personnel.
Inpatient	Psychiatric services in a residential, often hospital setting. (Page 39)
Least Restrictive Environment	An educational, treatment or living situation that provides appropriate services or programs for a child with handicaps while imposing as few limitations or constraints as possible. (Page 70)
Mainstreaming	Placement of a child with a handicap in the regular classroom. (Page 70, 71)
Major Depressive Episode	A mood disorder with a depressed mood that may accompany a manic episode. (Page 29)

Medicaid	Title XIX (19) funding for medical services for individuals receiving public assistance, or who are blind or disabled.
Mentally Ill	A general term applied to individuals suffering from severe emotional problems or psychiatric disorders. (Page 62)
Neurologically Impaired	Having damage or deficiency in the nervous system of the body. (Page 62)
Neurologist	A physician (M.D.) specializing in diagnosis and treatment of diseases of the nervous system. (Page 32)
Oppositional Disorder	The covert display of underlying aggression by patterns of obstinate, but generally passive behavior. Children with this disorder often provoke adults or other children by the use of negativism, stubbornness, dawdling, procrastination, and other behaviors. (Page 26)
Outpatient	Treatment available in the community at a local mental health clinic or from private therapists. Children receiving this type of treatment generally live at home. (Page 38)
Overanxious Disorder	Diffuse fears and worries that cannot be traced to specific problems or stresses. (Page 27)
Parent Training	1. Classes or individual instruction designed to improve parenting skills in such areas as discipline, consistency, and communication 2. Parent Training and Information (PTI) provides information and assistance to parents so they can be knowledgeable and effective advocates within service and policy systems.
Pediatric RN	A registered nurse specializing in the care of children.
Pervasive Developmental Disorder	Extreme distortions or delays in the development of social behavior and language. (Page 28)
Post-traumatic Stress Disorder	Anxiety disorder following a traumatic event. (Page 27)

Psychiatric Nurse	A registered nurse specializing in the care of patients with emotional or psychiatric disorders. (Page 35)
Psychiatric Social Worker	Social worker specializing in work with psychiatric patients and their families. (Page 35)
Psychiatrist	A physician (M.D.) specializing in mental, emotional, or behavioral disorders. Qualified to prescribe medications. (Page 34)
Psychoanalyst	A person who diagnoses and treats emotional disorders through special techniques that explore a patient's mental and emotional makeup. This approach to treatment is usually long term. (Page 34)
Psychologist	See Clinical Psychologist.
Psychosis	A general term used to describe any of several mental disorders characterized by social withdrawal, distortions of reality, loss of contact with environment and disintegration of personality. (Page 30)
Psychotherapist	A mental health professional who provides psychotherapy. (Page 34)
Psychotherapy	A broad term applied to a variety of approaches to the treatment of mental and emotional disorders. (Page 24)
Residential Treatment	Live-in facilities that provide treatment and care for children with emotional disturbances who require continuous medication and/or supervision or relief from environmental stresses. (Pages 38, 39)
Respite Services	Temporary care given to an individual for the purpose of providing a period of relief to the primary caregivers. Respite is used to decrease stress in the homes of persons with disabilities or handicaps, thereby increasing caregivers' overall effectiveness. (Page 41, 42)
Schizophrenia	A serious mental disorder characterized by verbal incoherence, severely impaired interpersonal relations, disturbance in thought processes, cognitive deficits, and inappropriate

	or blunted affect. The child may also exhibit hallucinations or delusions. (Page 30)
School Phobia	Fear of going to school associated with anxiety about leaving home and family members. (Page 27)
School Psychologist	A mental health professional who works in schools. (Page 34)
School Social Worker	A social worker who works in schools. (See Social Worker)
Screening	An assessment or evaluation for the purpose of determining the appropriate services for a client.
Seriously Emotionally Disturbed or Severely Emotionally Disturbed	A child or adolescent who exhibits behavioral, emotional and/or social impairment that consequently disrupts the child's or adolescent's academic and/or developmental progress, family and/or interpersonal relationships, and has impaired functioning that has continued for at least one year, or has an impairment of short duration and high severity. (Page 62, 64, 65)
Simple Phobia	Characterized by persistent irrational fears of a specific object, activity, or situation. (Page 27)
Social Worker	A professional trained to provide services to individuals, families, and groups. (Page 34)
Socially Maladjusted	Having extreme difficulty dealing appropriately with other people. (Page 62)
Sociopath	A term sometimes used to describe persons with extreme disregard for and hostility toward society.
Status Offense	Non-criminal behavior of a child such as running away, truancy, and curfew violation, that can result in juvenile court action.
Support Services	Transportation, financial help, support groups, homemaker services, respite services, and other specific services to children and families.
Treatment	Changing behaviors or other conditions related to the child's emotional handicap; and/or helping the individual and his or her family to cope with the handicap.

Treatment Modality	The method that is used to treat a child; for example, behavior management is one treatment modality and play therapy is another.
Wechsler Tests	A series of verbal and performance tests widely used in school systems. Three types are used: 1. WPPSE: The Preschool and Primary Scale of Intelligence 2. WAIS-R: The Adult Intelligence Scale (Revised) 3. WISC or WISC-R: The Intelligence Scale for Children (Revised)
Withdrawing Behavior	Behavior characterized by reduced interest in or contact with other people, and can include absence of speech, regression to babyhood, exhibition of many fears, depression, refusing contacts with other people. (Page 3)

GLOSSARY ACKNOWLEDGEMENTS

The majority of the information in this glossary is taken from the text of *Taking Charge*. Page numbers after terms in the glossary refer to pages in this publication. Additional definitions were taken from the Idaho Child and Adolescent Services System Program (CASSP) Glossary or were contributed by staff members of the Families as Allies Project.

Certain acronyms were defined by staff members of their organizations. Some of these were Mental Health Association (MHA), defined by Diane Luther of the Salem, Oregon, Mental Health Association; Migrant Program Branch (MPB), defined by Penny Hinkley of the Oregon Migrant and Indian Coalition Head Start, a Migrant Program Branch organization; State Mental Health Representatives for Children and Youth (SMHRCY), defined by Lenore Behar, Ph.D., Chief, Child Mental Health Services, North Carolina Department of Human Resources; and anonymous authors of brochures distributed by the National Information Center for Children and Youth with Handicaps (NICCYH) and the Association for the Care of Children's Health (ACCH). Certain terms were defined by experts in the field. These include the definition of "exceptional children" by Richard J. Sonnen, Ed.D., Department Head, Special Studies, Portland State University, Oregon; "community support system" by the Department of Health and Human Services Steering Committee on the Chronically Mentally Ill, 1980; and "emotionally disturbed," "seriously emotionally disturbed," and "behavior disordered" by Vermont Child and Adolescent Services System Program (CASSP). The definitions of "schizoid disorder"and "schizophrenic disorder" are taken from *Behavior Disorders in Infants, Children, and Adolescents* edited by John M. Reisman (1986), New York: Random House. Another reference source is *Women and Psychotherapy: An Assessment of Research and Practice* edited by Annette Brodsky and Rachel Hare-Mustin (1980), New York: Guilford Press.

The Families as Allies Staff offered suggestions on the content of the glossary and assisted in locating and defining acronyms and terms. Marilyn McManus proofread the glossary and offered suggestions for its improvement. Barbara Friesen originated the idea of developing a glossary of acronyms and terms as a service to families of children with emotional disturbances.

TAKING CHARGE: A HANDBOOK FOR PARENTS WHOSE CHILDREN HAVE EMOTIONAL HANDICAPS

EVALUATION FORM

1. Who used *Taking Charge*? (Check all that apply.)

___Parent ___Educator ___Child Welfare Worker

___Juvenile Justice Worker ___Mental Health Professional

Other (Please specify) ______________________________

2. Please describe the purpose(s) for which you used the handbook:

____

____

____

3. Would you recommend use of *Taking Charge* to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

Comments: ______________________________

4. Overall, I thought *Taking Charge* was: (Circle one)

Excellent Average Poor

Comments: ______________________________

5. Please offer suggestions for the improvement of subsequent editions of this handbook:

____

____

____

____

____

We appreciate your comments and suggestions. Your feedback will assist us in our effort to provide relevant and helpful materials. Thank you.

Please fold, staple and return this self-mailer to the address listed on the reverse side.

fold and staple

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL

FIRST CLASS PERMIT NO. A-75 PORTLAND, OREGON

POSTAGE WILL BE PAID BY ADDRESSEE

RESEARCH AND TRAINING CENTER
REGIONAL RESEARCH INSTITUTE FOR HUMAN SERVICES
PORTLAND STATE UNIVERSITY
P.O. BOX 751
PORTLAND, OR 97207

Research and Training Center Resource Materials

☐ *Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals.* Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines. $3.00 per copy.

☐ *Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention.* Transition needs of adolescents: educational and vocational issues, programs and curriculum, research overviews, interpersonal issues, skills training. One copy free while supplies last.

☐ *Child Advocacy Annotated Bibliography.* Includes selected articles, books, anthology entries and conference papers written since 1970, presented in a manner useful to readers who do not have access to the cited sources. $7.00 per copy.

☐ *Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families.* Held in April 1986 and attended by delegations from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketches, recommendations, worksheets, and evaluations. $6.50 per copy.

☐ *Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children.* Findings from Idaho, Oregon, and Washington, covering current services, successes, service delivery barriers, exemplary programs and innovations. $2.00 per copy.

☐ *Glossary of Acronyms, Laws, and Terms for Parents Whose Children Have Emotional Handicaps.* Glossary is excerpted from the *Taking Charge* parents' handbook. Approximately 150 acronyms, laws, and words and phrases commonly encountered by parents whose children have emotional handicaps are explained. $1.00.

☐ *Making the System Work: An Advocacy Workshop for Parents.* A trainers' guide for a one-day workshop designed to introduce the purpose of advocacy, identify sources of power and the chain of command in agencies and school systems, and practice advocacy techniques. $5.00.

☐ *The Multnomah County CAPS Project: An Effort to Coordinate Service Delivery for Children and Youth Considered Seriously Emotionally Disturbed.* A process evaluation of an interagency collaborative effort is reported. The planning process is documented and recommendations are offered. $3.00 per copy.

☐ *National Directory of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth.* The U.S. organizations included provide one or more of the following services: education and information, parent training, case and systems level advocacy, support groups, direct assistance such as respite care, transportation and child care. $5.00 per copy.

☐ *Parents' Voices: A Few Speak for Many* (videotape). Three parents of children with emotional handicaps discuss their experiences related to seeking help for their children (45 minutes). A trainers' guide is available to assist in presenting the videotape. Free brochure describes the videotape and trainers' guide and provides purchase or rental information.

☐ NEW! *Respite Care: An Annotated Bibliography.* Thirty-six articles addressing a range of respite issues are summarized. Issues discussed include: the rationale for respite services, family needs, program development, respite provider training, funding, and program evaluation. $2.50 per copy.

☐ NEW! *Respite Care: A Monograph.* More than forty respite care programs around the country are included in the information base on which this monograph was developed. The monograph describes: the types of respite care programs that have been developed, recruitment and training of respite care providers, the benefits of respite services to families, respite care policy and future policy directions, and a summary of funding sources. $2.00 per copy.

☐ REVISED! *Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps.* The handbook addresses issues such as parents' feelings about themselves and their children, labels and diagnoses, and legal issues. The second edition expands upon emotional disorders of children, including post-traumatic stress disorder and mood disorders such as childhood depression and bipolar disorder. Single copies free to parents whose children have emotional handicaps while supplies last. All others, $7.00 per copy.

☐ *Working Together: The Parent/Professional Partnership.* A trainers' guide for a one-day workshop for a combined parent/professional audience. Designed to identify perceptions parents and professionals have of each other and obstacles to cooperation; as well as discover the match between parent needs and professional roles, and practice effective listening techniques and team decision making. $5.00.

Order form on reverse ☞

ORDER FORM AND MAILING LIST Research and Training Center

☐ Please send me the publications checked on reverse. $________ enclosed as appropriate.

☐ Add me to your mailing list. ☐ Take me off your mailing list.

☐ Change my address as noted below.

NAME____

ORGANIZATION____________________________________

STREET ADDRESS__________________________________

CITY/STATE/ZIP__________________________________

TELEPHONE_______________________________________

CHECKS PAYABLE TO: Portland State University
MAIL TO: Resource Services Coordinator, Research and Training Center, Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751, (503) 464-4040

Portland State University
Research and Training Center
Regional Research Institute for Human Services
P.O. Box 751
Portland, Oregon 97207-0751

Nonprofit Org.
U.S. Postage
PAID
Portland, OR
Permit #770